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Portfolio of Doctorate in Health Psychology

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For the qualification of
Professional Doctorate in Health Psychology

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Acknowledgments

I would like to express my sincere gratitude to my academic supervisor Dr. Angeliki Bogosian, for her sustained support and guidance throughout this process. Angeliki has been an unlimited source of advice and encouragement. She has always been available to provide insight, offer practical direction and has been extremely generous in sharing her time, experience and expertise. I will remain deeply appreciative of all her help during the training.

I would also like to express my gratitude to Dr Hayley McBain for her help with the final stages and to the academic staff team at City, University of London, as well as to all of the participants who gave up their time to take part in this study.

My eternal appreciation goes to my wife Basia, without whom it would not have been possible to complete this process. I would like to thank her for all the help, patience and consideration during the training. Most of all, I will remain everlastingly grateful that I have been able to share some of the best moments of my life with her over the last three years.

My sincerest thanks go out to all the friends and family who have supported me throughout the training, particularly my father, Iftikhar Satti for teaching me how to take the time to appreciate the finer things in life. Special thanks go to my sister, Nusrat Ahmed for all her help with the proof reading.

I dedicate this thesis to my son Mikael, whose arrival provided me with the final spur required in the acquisition of the qualification and to the two Sofia's; My mother, who has always taught me to believe in myself while providing me with unconditional love and support and my daughter, who has, and always will, inspire me to be the best that I can be.

SECTION A: PREFACE

This Portfolio documents completion of the required competencies for the award of Professional Doctorate in Health Psychology. It demonstrates the process of the acquisition of skills and knowledge while undertaking Health Psychology training. It focuses on reflections of linking the theoretical awareness that occurred during this process with applied areas of practice.

The majority of the training illustrated in this portfolio involved the application of Health Psychology theories and frameworks within a community based mental health project. Evidence suggests that on average, individuals with serious mental health illnesses such as schizophrenia, die twenty years earlier when compared with the general population. They are also twice as likely to develop diabetes, twice as likely to develop hypertension, three times more likely to die from coronary heart disease, ten times more likely to die from respiratory disease and four times more likely to die prematurely (Rethink Mental Illness, 2013). Additionally, weight gain is a common unwanted side effect of anti-psychotic medication (Kurzthaler & Fleischhacker, 2001). This has been identified as a crucial issue as many patients with schizophrenia are exposed to serious health risks due to excessive body weight (Acil, Dogan, & Dogan, 2008). The clinical implications of these factors are pronounced, particularly when the financial connotations are considered. Hospital treatment and anti-psychotic medication can be both costly and prolonged in long-term mental health disorders (Allison et al., 2009). Additionally, research suggests that a lack of

knowledge of the positive aspects of healthy living is prevalent on many mental health wards (Acil et al., 2008). Furthermore, individuals diagnosed with mental illness often display a lack of engagement and trust towards health care professionals. Due to this, their physical health and overall well-being can often be overlooked (Acil et al., 2008). Developing an effective therapeutic relationship is often considered a cornerstone to effective treatment (Lehrer & Lorenz, 2014), and communication has been identified as having a significant impact on therapeutic relationships for individuals diagnosed with schizophrenia. Communication styles and effective health promotion could therefore potentially have a profound impact upon patients.

The training was conducted within the context of these factors. The aim was to utilise this opportunity to introduce the benefits of the application of Health Psychology theory, within a community based mental health setting. Improving the health of this population was at the centre of many aspects of the portfolio. It was hoped that this could impact on overall well-being, enhancing standards and delivery of psychiatric care and conceivably serving as a pathway, which could potentially result in an uptake of Applied Health Psychologists working within this field.

The research thesis explored the concept of adherence to anti-psychotic medication. Anti-psychotic medication is the most common form of treatment for various forms of psychosis. However, many individuals avoid terms such as psychotic or schizophrenic, with some individuals rejecting their clinical diagnosis altogether. Therefore, the decision was made for terminology to focus purely on the medication rather than a particular condition. This was an effort to avoid labelling and to make the research as inclusive as possible while maximising patient participation. The aim was for the

research to benefit from a focus on patient perspectives in addition to clinical perspectives.

Anti-psychotic medication can deliver considerable improvements in symptoms. Yet, the estimated rate of non-adherence to anti-psychotics is reported to be 56% (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002). Non-adherence to anti-psychotic medication is associated with a range of detrimental outcomes including an increased risk of relapse and rehospitalisation, increased use of emergency psychiatric services, detrimental mental functioning and increased risk in suicide (Beck, Cavelti, Kvrjic, Kleim, & Vauth, 2011). Investigating ways of improving adherence was thus seen as a crucial element of future research (Acosta, Hernández, Pereira, Herrera, & Rodríguez, 2012). The aim was for the thesis to be written in a manner which would be accessible not only to Health Psychologists but also to those working within mental health settings. The potential real-world impact is presented in the wider context of the value of the theoretical frameworks of Health Psychology in exploring these phenomena. The implications of how the Self-Regulation Model provides a useful framework for understanding how a patient's representation of their illness influences their adherence to anti-psychotic medication is a key element of the results of this study. The findings from the research thesis are due to be presented at the BPS Division of Health Psychology conference in September 2017.

Having identified issues surrounding the prevalence of physical health and weight gain amongst individuals prescribed anti-psychotic medication, it was apparent that a healthy eating behaviour change intervention would be of considerable benefit in

optimizing well-being of service users within a community based mental health setting. To this end the behaviour change competency focused on the development and implementation of Health Psychology based behaviour change workshops. This provided service users with an opportunity that they might not otherwise receive and further amplified the real-world potential and benefits of the application of Health Psychology theory and input within a mental health setting.

Health Psychology and health promotion are complimentary and proved to be an antecedent to first component of the teaching and training competency. During discussions with a director at a community mental health service, the impact of the behaviour change competency was assessed. It was agreed that raising awareness of the benefits of healthy eating, focusing specifically on aiding service users within mental health settings, would be of great use to staff members within the organisation. The director was eager for training on Health Psychology perspectives to be rolled out to the multi-disciplinary staff team. Training was adapted to focus on communication styles and introduced Motivational Interviewing as a useful technique in helping people change health related behaviour in mental health settings.

Throughout the course of the training there were numerous opportunities to lecture on various undergraduate and postgraduate psychology programmes. The case study included in this portfolio focuses on a lecture on the Research in Action module, which explored the psychological impact of Alopecia (the area of the systematic review), as this lecture was designed purely from the research undertaken while carrying out work for this portfolio. The process of designing and conducting a lecture which helped disseminate findings to post graduate psychology students proved to

be an extremely worthwhile and enjoyable experience. It provided the opportunity to develop new skills and was a particular highlight of the training process.

The concept for the systematic review, developed from an interest in the promotion and engagement of psychological interventions for relatively obscure conditions. This stemmed from a conversation with an Alopecia patient in which their experiences of the condition were described. It was highlighted how family members had suggested that it was vain to focus on physical appearance. While healthcare professionals emphasised that it did not involve physical pain, and had expressed how the individual should be grateful that the hair loss was not due to a more serious illness such as cancer. This was paralleled with the experience of working with individuals diagnosed with mental health conditions. Some of whom had described frustrations at how, many of their symptoms such as lack of motivation, were often viewed as behavioural issues and not as symptoms of their illness. Alopecia is not life threatening, it does not involve loss of mobility or physical pain. However, it can have a profound negative impact on one's psychological health (Williamson, Gonzalez, & Finlay, 2001). A systematic review was conducted to develop a more detailed understanding of the psychological and social impact of Autoimmune Alopecia and the psychological treatments currently available for this impact.

The consultancy involved the opportunity to work with a different client group in the area of smoking cessation. Smoking is a complex health behaviour involving an amalgamation of biological, psychological and social processes (Marks, Murray, Evans, & Willig, 2000). Addiction to smoking and the process of cessation is an im-

portant area for Health Psychology practice and research, and a priority for the government in reducing health inequalities, while improving overall health. Although the trainee was experienced and qualified in providing specialist smoking cessation support amongst mental health populations, working with a completely different client group afforded the option to develop new skills, expand upon communication techniques and hone pre-existing skills. The Consultancy, Teaching and Training and Systematic Review thus provided an opportunity to work with different populations. This has demonstrated that although there was a core emphasis during the training, there has also been variety, highlighting the scope of Health Psychology to be applied within a diverse range of settings.

This portfolio demonstrates the consolidation of learning and experience on the doctoral Health Psychology training programme. The varying competencies illustrate the process of the application of theory to practice and assessing and critiquing the evidence base to address challenges. The main focus was on the application of Health Psychology principles, while working as a Trainee Health Psychologist in a community based mental health project. Working within this setting provided innovative ways to expand upon the boundaries of its implementation, expounding the numerous benefits of its applications, and illustrating the positive role that Health Psychology can play in addressing key public health challenges.

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SECTION B: RESEARCH

An Investigation into Determinants of Adherence to Anti-Psychotic Medication

Abstract

Introduction

Adherence to prescribed medication is crucial to effective treatment in many chronic conditions, and particularly for individuals diagnosed with psychosis. Health Psychology has traditionally provided robust models that have been employed to explore adherence in numerous chronic conditions. However, research using these models to explore adherence to anti-psychotic medication is scarce. This study looked to implement the science and evidence base of Health Psychology while exploring determinants of adherence to anti-psychotic medication.

Method

In this longitudinal questionnaire study, data was collected at two-time points, six months apart. One hundred and ten individuals participated in the baseline stage. Adherence to antipsychotic medication was measured using the Medication Adherence Rating Scale. Social support, illness perceptions, illicit drug use and side effects were assessed using the Duke Functional Social Support Questionnaire, The Brief Illness Perception Questionnaire, The Drug Abuse Screening Test and The Glasgow Anti-Psychotic Side Effect Scale Questionnaires respectively. Analysis of Variance and Correlation analyses were conducted to explore associations between these

factors and adherence, while the potential predictive capacity of these factors was examined through Multiple Regressions.

Results

Social Support, Treatment Control and Personal Control were significantly associated with adherence, while Treatment Control ($\beta=.407$ [.405-.095], $p=.000$) and Social Support ($\beta=.282$ [.682-.214], $p=.002$) were demonstrated to be a significant determinant of adherence to anti-psychotic medication.

Conclusion

Adherence to anti-psychotic medication presents with a unique set of challenges and is a complex phenomenon influenced by a number of parameters. Levels of social support and treatment control are significant determinants of adherence to anti-psychotic medication. Efforts to enhance social support and personal control can be employed in future interventions designed to increase adherence. Treatment Control is an important factor and the Self-Regulation Model has the aptitude to be employed in future research. There is potential for prospective research to apply Health Psychology theories, frameworks and principles to not only scrutinise adherence within mental health settings but also develop behaviour change interventions that target identified risk factors for non-adherence.

SECTION 1. INTRODUCTION

CHAPTER 1. Adherence

1.1 Adherence and Health Psychology.

Non-adherence is an intricate, multi-factorial issue with a variety of forms. The challenges of patients not following prescribed treatment is not new. Indeed, it was commented upon by Hippocrates in the 4th century BC (Lerner, 1997). It is a problem in all areas of medication but the very nature of psychiatric illness, which can have an impact upon judgment, places psychiatric patients at increased risk of non-adherence (Srinivasan & Thara, 2002).

Adherence is a behaviour that is difficult to detect and individuals may be fully or partially non-adherent (Schennach-Wolff et al., 2009). Researchers have suggested that adherence to medication ranges on a spectrum. From patients who take none of their prescribed medication, to those who take every dose exactly as described, with various levels in between which can be termed as partial adherence (Haddad, Brain, & Scott, 2014). In research, adherence is often dichotomised for analysis requirements and a distinction made at missing 20% of medication, as this termination point has been demonstrated to have validity in predicting subsequent rehospitalisation in psychosis (Karve et al., 2009). However, others have argued that adherence should be viewed as continuously disturbed rather than naturally dichotomous, as complete adherence or non-adherence is uncommon (Razali & Yusoff, 2014).

Health Psychology has proposed various models to explain the psychological factors affecting non-adherence, several which will be discussed in this study. Leventhal's (1980) Self-Regulation Model has frequently been utilised to explain adherence in long-term conditions. More recently, the Necessity-Concerns Framework (Horne et al., 2013) has expanded upon previous research and outlined how common sense evaluations of prescribed medication influence the motivation to adhere to treatment. Models such as Leventhal's Self-Regulation model and the Necessity-Concerns Framework have been used to explore adherence in numerous long-term conditions. However, research into the application of Health Psychology frameworks amongst individuals diagnosed with psychosis remains scarce, and there is a deficiency of in-depth, longitudinal reviews of the unique factors surrounding adherence amongst a population of individuals prescribed anti-psychotic medication. This study looked to implement the science and evidence base of Health Psychology and Health Behaviour Change into the world of adherence to anti-psychotic medication.

1.2 Adherence and Anti-psychotic medication.

Antipsychotic medications are primarily indicated for the treatment of the symptoms of psychoses. Psychosis is the term used to refer to the experience of hallucinations (sensory perceptions of phenomena that are not actually present) and delusions (false beliefs held despite evidence to the contrary) and the resulting behaviour that may occur as a consequence of these experiences. Illnesses involving symptoms of psychosis include schizophrenia and other psychotic disorders such schizoaffective

disorder, delusional disorder and bipolar affective disorder, Antipsychotic medications may also be used to treat the psychosis associated with other medical conditions, such as dementia (Lally & MacCabe, 2015).

According to statistics released in 2015 by the Health and Social Care Information Centre, one in four people in the UK report being diagnosed with at least one mental health problem (The Health & Social Care Information Centre, 2015). Schizophrenia is the traditional term for more severe psychoses. Schizophrenia is one of the most common severe mental health conditions, for many it is a chronic psychotic disorder, which causes a range of different psychological symptoms and has substantial emotional and financial impact (Popp, Manea, & Moraru, 2014). It is a disorder that affects thinking, feeling and behaviour. Symptoms can include delusions, hallucinations such as hearing voices, and loss of interest, energy and emotions. The cost and impact of psychosis, both to the individual and at a societal level can be immense (Zou et al., 2013). Periods of remission and relapse are often precipitated by dysautonomia (i.e. dysfunction of autonomic nervous system), isolation and financial dependence (Popp et al., 2014).

This research will examine adherence to anti-psychotic medication in general rather than focus on a particular medication or condition due to patients' preference to avoid labelling and difficulties with accurate diagnosis. During the Patient and Public Involvement (PPI) groups conducted as part of this study (refer to chapter 8.4), it was highlighted that patients often felt labelled and stigmatised by terms such as "schizophrenic" and often disassociate from such terminology, many reported that they would feel more comfortable taking part in research focusing on their medication rather than their condition. Furthermore, a diagnosis of schizophrenia is made based

on psychiatric evaluation identifying the presence of two or more of the following symptoms for over 30 days; hallucinations, delusions, disorganized speech, catatonic behaviour or negative symptoms (emotional flatness, apathy, lack of speech). As symptoms and Community Mental Health teams had varied over time, feedback from the PPI suggested that it was common to have multiple diagnoses at a particular time or to be diagnosed with different conditions by different psychiatrists during the course of treatment. In addition, it was highlighted that the majority of patients were treated with a combination of different anti-psychotic medications rather than just one and that it was relatively common for the psychotropic medication to be changed numerous times during treatment. Therefore, this study will focus on patients' illness perceptions and adherence to medication in general and will not make any distinction of the specific medication taken. This was an effort to avoid labelling and to make the research as inclusive as possible while maximising patient participation.

1.3 Unique aetiology of psychosis.

An important point to consider when investigating adherence to anti-psychotic medication is the unique aetiology of the condition. Historically, treatments for those suffering from psychoses were often ineffectual and many remained in asylums for lengthy periods. However, the introduction of anti-psychotic medications in the 1950's enabled those diagnosed with mental health disorders to be treated in the community. The conception of typical antipsychotic medication and subsequent introduction of atypical antipsychotics has resulted in improved outcomes for patients, moving away from Victorian modes of treatment in outdated wards and instigated

the introduction of community care (Coffey, 1999). Anti-psychotic medication is considered a cornerstone in the treatment and recovery of severe mental health illnesses such as schizophrenia (McCann, Boardman, Clark, & Lu, 2008). Overwhelming evidence suggests that anti-psychotic medication is extremely efficacious in treating the symptoms of psychosis (Thornley & Adams, 1998). It has the potential to reduce the risk of relapse substantially (Klingberg, Schneider, Wittorf, Buchkremer, & Wiedemann, 2008). Numerous studies have highlighted that the key element of favourable long-term outcomes is continuous adherence to anti-psychotic treatment (Robinson et al., 2002; Malla et al., 2006).

The development, progression, consequences and outcomes in psychosis vary greatly between individuals (Ram, Bromet, Eaton, Pato, & Schwartz, 1992). A relatively low percentage of people diagnosed experience a single episode and fully recover. For the majority, it is a chronic condition. However, the prognosis is favourable when treated with anti-psychotic medication (Haddad et al., 2014). Research suggests that long-term treatment adherence to anti-psychotic medication coincides with considerable improvements in symptoms and functioning and it therefore has a substantial advantage over no treatment or non-adherence (Lee, Kane, Sereika, Cho, & Jolley, 2011). Despite the evidence suggesting that anti-psychotic medication is imperative in the successful treatment of psychosis, it is reported that schizophrenia is the second most difficult condition in which to obtain suitable adherence, with the most difficult being weight reduction therapy (Keith & Kane, 2003). The estimated rate of non-adherence in schizophrenia is reported to be 56% (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002). However, prevalence rates vary according to clinical setting, assessments used, duration, and study population characteristics (Novic et al.,

2010). In the first two years subsequent to a psychotic episode, the non-adherence rate is reported to be 55% and is linked to a fivefold increase in rehospitalisation within one year (Barkhof, Meijer, de Sonnevile, Linszen, & de Haan, 2012).

In severe psychiatric conditions where insight is often impaired, and the necessity of treatments may not be recognised by the patient (Emsley, 2010), non-adherence can be a convoluted, severe issue. In fact, a recent review highlighted several features that make non-adherence especially challenging for psychiatric patients. These factors not only include a lack of illness awareness (which refers to illness perceptions and insight as well as beliefs and attitudes concerning the composition of the illness), the direct impact of symptoms (which can include cognitive impairments, depression and both positive and negative symptoms), comorbid substance misuse, social isolation, stigma and increasing disintegration of mental health services in many societies (Haddad et al., 2014). However, while a number of studies have investigated these concepts separately there is relatively scarce longitudinal research exploring the interaction between these factors.

1.4 Research impediments and distinction between Compliance & Adherence

There are also complexities in the definition of compliance or non-adherence and the criteria by which it becomes clinically relevant (Kikert et al., 2008). In general terminology, adherence to a medication regime is viewed as the extent to which the indi-

vidual's behaviour corresponds with agreed recommendations from a health professional (Lehane & McCarthy, 2009). The term "non-adherent" may refer to other treatment recommendations and not just medication. This is recognised by the World Health Organisation (Haddad, Brain & Scott, 2014). In secure mental health wards, the term compliance is often used rather than adherence. Compliance refers to "the extent to which the patient's behaviour (in terms of taking medications, following diets, or executing other lifestyle changes) coincides with medical recommendations" (Haynes, 1979). Adherence refers to "the extent to which the patient's behaviour (in terms of taking medications, following diets, or executing other lifestyle changes) coincides with medical recommendations jointly agreed between the patient and the prescriber" (Barofsky, 1978). The difference between the two terms mainly involves the responsible clinicians' degree of authority and any other distinction is negligible (Acosta et al., 2012). However, the term adherence emphasises patient autonomy whereas the term compliance is often criticised as being overly authoritarian, illustrating a hegemony in the relationship. In spite of this, the term compliance remains in consistent use in mental health setting parlance (Ziguras et al., 2001). The term concordance has been used to outline mutual agreement while encompassing patient support in taking medication. A range of alternative terms have been proposed including treatment compliance and fidelity, however adherence is generally preferred due to its neutrality (Haddad, Brain & Scott, 2014). For this reason, the term adherence will be used throughout this study. Additionally, adherence is a behaviour that is difficult to detect and individuals may be fully or partially non-adherent (Wolf et al., 2009).

It is also difficult to distinguish between intentional and non-intentional non-adherence. Individual perception and practicalities can impede a distinction between unintentional non-adherence, which is non-adherence due to lack of capacity, resources and other practical factors and intentional non-adherence which is non-adherence due to motivational beliefs, preferences and other perceptual factors (Horne, 2001). Unintentional non-adherence to treatment may be due to lack of understanding of the treatment regime. Based on this premise, the target is to enhance knowledge, skills and awareness, which is necessary and beneficial. Another reason for unintentional non-adherence may be due to retrospective memory. Patients forget the details of the treatment regime. If that is the case, patients may benefit from written or even illustrative examples of the regime. A third reason for unintentional non-adherence may be that patients forget their postponed intention of what to do at the time when they are supposed to recall their intention to do it (Park and Kidder, 1996). Retrieval can be improved by event based retrieval or time based retrieval. Or making an implementation intention, delegating control to the environment by specifying where, when and how to adhere to medication. The focus of the present study will be on intentional adherence. The problem with targeting unintentional adherence is that education, knowledge and memory cues do not often predict better adherence when non-adherence is deliberate. The predictors of intentional adherence have been modelled in the same way as other health behaviours. In the present study cognitive determinants of adherence as well as demographics and social support will be explored.

Researchers (Haddad, Brain & Scott, 2014) suggest that adherence to medication ranges on a spectrum, from patients who take none of their prescribed medication,

to those who take every dose exactly as described, with numerous other levels in between which can be termed as partial adherence. However, in research adherence is often dichotomised for analysis requirements and a distinction made at missing 20% of medication as this termination point has been demonstrated to have validity in predicting subsequent rehospitalisation (Karve et al., 2009). Conversely, others have argued that adherence should be viewed as continuously disturbed rather than naturally dichotomous as complete adherence or non-adherence is uncommon (Razali & Yusoff, 2014). Therefore, for the purpose of this research, adherence is considered to be on a continuous spectrum rather than dichotomised.

1.5 Depot neuroleptics provided in long-acting injections.

Long acting depot injections offered in the form of depot neuroleptic medication were identified as a means of improving adherence and relapse prevention when they were first introduced in the United Kingdom in 1966 (Tattan & Creed, 2001). The first atypical neuroleptic to be produced in depot form is Risperidone, a commonly prescribed atypical anti-psychotic originally available in oral form. The influence of depot risperidone in clinical settings has resulted in other atypical neuroleptics becoming available in the form of long-acting injections including paliperidone depots and olanzapine depots both of which have the additional advantage of being available on a monthly rather than fortnightly basis. Some typical anti-psychotic medications such as haloperidol and fluphenazine are also available in long-acting injection formulations. The advantage of depot neuroleptics, in the form of long-acting injections, is

the simplification of the administration of the medication. The patient does not administer the medication themselves, providing opportunities for monitoring, review and regular patient contact. There are less associated issues surrounding obtaining prescriptions or collecting medication.

There are a range of political reasons for the use of long acting depot injections, as it associated with increased cost savings (Aldridge, 2011). Depot injections are normally administered by a Registered Mental Health Nurse and their administration is often used as an opportunity for patient contact, monitoring and termed as a review. This can lead to job losses for community social workers and other health care professionals who would normally provide these fortnightly reviews. However, there is prevalent research suggesting that long acting depot injections are more coercive than oral antipsychotics, with considerable ethical concerns regarding the coercion and force associated with long acting depot injections in the mental health system, which continues to be debated among psychiatrists and nurses (Patel et al. 2010). Despite these concerns, British legislation has enhanced authority to mandate adherence with treatment for patients in the community (Molodynski et al. 2010). Supervised community treatment orders (CTOs), were first introduced in 2008. Under supervised community treatment, individuals are made subject to a CTO, CTO conditions can be used to legally enforce adherence to a long acting depot injection in the community with one of the most frequent CTO conditions involving a requirement to adhere to treatment, that often includes anti-psychotic depot injections (Emsley, 2010). This further politicises the debate as there is a strong CTO focus on antipsychotic depot injections. Breaching CTO conditions through non-adherence to a prescribed depot injection could be used as grounds for recall to hospital even in the

absence of relapse (Molodynski et al. 2010). This can also be viewed as the most severe potential disadvantage of long-acting depots, as they are often perceived as more coercive than oral anti-psychotics and have faced ethical challenges as research indicates that patients report long-acting depot injections as the least preferred of the various types of psychiatric medications, with some patients finding the process demeaning (Aldridge, 2011).

At present, there is limited evidence sourced from randomized controlled trials regarding the safety and efficacy of long-acting depot injections compared with placebo or oral anti-psychotic medication (NCCMH 2010). It has also been highlighted that relapse can occur even when medication is administered by long-acting depot injections (Aldridge, 2011). An in-depth review also found that one year after hospital discharge there were no differences in rates of adherence to depot or oral anti-psychotic medication (Weiden et al., 1996).

Aldridge (2011) suggests that if non-adherence still occurs while patients are prescribed long acting depot injections, a planned non-adherence harm-reduction approach would potentially reduce harm. This would involve providing information and resources on coming off anti-psychotic medication. Monitoring, close support, and the use of psychosocial interventions for coping with stress could potentially help to lessen possible harm resulting from withdrawal (Wunderink et al. 2007). Aldridge (2011), goes on to argue that a harm-reduction approach to non-adherence is more in accord with nursing as seen in both the NMC (2008) Code and the Prime Minister's Commission on the Future of Nursing and Midwifery in England (2010).

1.6 Temporal Effects of the condition

Most individuals will be prescribed anti-psychotic medication following a psychotic episode and may not yet themselves be acutely aware of the extent of the illness or their diagnosis. A common symptom of psychosis is hallucination (both auditory and visual), which can make it difficult to distinguish reality from delusion. Individuals diagnosed with a psychosis often suffer from impaired insight and may not recognise the necessity of treatment (Emsley, 2010). This can have a significant impact as the temporal effects can influence beliefs and outcomes in the illness. Patients may have suffered from an acute psychotic episode and may not have consented to treatment, resulting in sectioning under the Mental Health Act (1983) and in-patient treatment against the patient's will. In such scenarios, non-adherence to anti-psychotic medication may be exacerbated by their associations with traumatic experiences at in-patient settings, and of the higher doses of medication required in the acute stages of the illness (Coffey, 1999). Furthermore, some patients may find it difficult to distinguish side effects from the symptoms of psychosis (McCann, Clarke, & Lu, 2009), while others may be prescribed numerous anti-psychotic medications (Valenstein et al., 2004). Therefore, due to the length of time it takes to have an impact on symptoms, some people may not associate anti-psychotic medication with improvements in their mental health. There are also issues with the terminology and measures utilised within mental health settings, where individuals who do not adhere to an aspect of their treatment programme are termed "non-compliant" and researchers have highlighted limitations in the measures utilised to assess compliance (Acosta et al., 2009).

Often the individual will enter the mental health system in a crisis and will be treated with anti-psychotic medication. However, although anti-psychotic medication is effective in reducing symptoms (McCann et al., 2009), this effect can customarily take a considerable amount of time to manifest. The individual may therefore, not necessarily equate the medication with an improvement in their symptoms. Thus, the importance of continuing with the medication may not be obvious to patients who may attribute the alleviation in symptoms with other factors and may wish to put this distressing episode and its associations behind them (Sapra et al., 2014).

1.7 Impact of non-adherence to anti-psychotic medication.

Non-adherence is considered the main hindrance in psychosis treatment (Corrigan, 2002). With medication non-adherence considered a central barrier in the treatment of patients suffering from schizophrenia (Jaeger, WeiBhaupt, Flammer, & Steinert 2014). Prevalence, consequences and associated costs of non-adherence have ensured that the analysis of this trend is extremely relevant (Acosta et al., 2012). Non-adherence to anti-psychotic medication is associated with substantially detrimental treatment outcomes including risk of relapse, rehospitalisation, reduced psychosocial functioning (Weiden, Kozma, Grogg, & Locklear, 2004), increased use of emergency psychiatric services, poorer prognoses, detrimental mental functioning and increased risk in suicide (Beck, Cavelti, Kvrjic, Kleim, & Vauth, 2011).

The consequences of non-adherence can be overwhelming for patients and those close to them. Furthermore, research indicates that non-adherence is associated with a higher proclivity towards violence and related arrests, victimisations, increased illicit substance use, alcohol related problems, and significantly lower life satisfaction (Ascher-Svanum et al., 2006). Swartz et al., (1998), reported that non-adherence to anti-psychotic medication is linked to a heightened tendency to commit violent acts such as homicide or suicide. It is also stated to be a risk factor in completed suicides (Emsley, 2010).

Similarly, studies suggest that partial adherence to anti-psychotic medication is just as detrimental to mental health and is equally as damaging as non-adherence (Llorca, 2008). A review of the effect of partial adherence to anti-psychotic medication emphasised that the risk of relapse increased even with moderate gaps in medication adherence (Masand, Roca, Turner, & Kane, 2009). Findings also propose that numerous adherence measures underestimate the prevalence of non-adherence and that many clinicians underrate poor adherence rates in their patients (Emsley, 2010). Adherence rates in individuals may vary over time. It is often higher immediately after a hospital discharge and deteriorates gradually (Kane, Kishimoto, & Correll, 2013). In a study which measured non-adherence rates in first episode psychotic patients, it was reported that one third admitted to hospital were non-adherent six months later (Kamali et al., 2006). A study of male first episode psychotic patients found that 53.6%, abandoned their treatment within the first year (Novak-Grubic & Tavcar, 2002). Studies have posited that the rates of relapse in patients with schizophrenia increase almost fivefold after five years and reaches 81.9% (Theisen, 2001). In 2007, it was suggested that the annual cost associated with the

treatment of schizophrenia in the United States was over \$10 billion and that 40% of those costs were attributed to non-adherence (Byerly, Nakonezny, & Lescouffair, 2007). It is also important to note that relapse episodes involve more care related costs which in the UK places increasing financial and administrative burden not only on the NHS but also on local councils (Acosta et al., 2012).

According to figures from a British Broadcasting Corporation (BBC) report based upon research conducted in March 2015 the funding for NHS trusts to provide mental health services was £6.6 billion in 2014 (BBC 2015). The Health and Social Care Information Centre suggests that the social care expenditure on adults with mental health needs in the United Kingdom was £1.2 billion. The average cost of a night in a mental health in-patient bed is £321 - meaning a typical admission of 38 days costs over £12,000. However, in the current economic climate, these figures have come under increasing scrutiny, and reports indicate that funding for NHS trusts to provide mental health services have fallen by 8.25 per cent, or £600 million, over the course of the last government (BBC 2015). In 2012, the Schizophrenia Commission, a group of 12 independent experts, was established to review current understanding of schizophrenia and recommend priority actions to improve outcomes for patients. The commission reported that overall, the condition costs society almost £11.8 billion a year and recommended that funds should be reapportioned from secure care to community-based treatment programmes (The Schizophrenia Commission 2012). Thus, there is increasing financial and societal pressure on Community Mental Health Team's (CMHT's) to enhance adherence to anti-psychotic medication rates for those residing in the community.

1.8 Current perspectives.

Non-adherence to anti-psychotic medication is clearly a crucial predicament and failing to adhere to prescribed treatment is a central factor in relapse (Kane, 2007; Llorca, 2008; Masand et al., 2009). The costs of poor adherence are considerable to the patient and society. Exploring ways of improving adherence is thus seen as a key element of future research (Acosta et al., 2012; Srinivasan & Thara, 2002). The dynamics that influence the individual's level of adherence can be described as an interaction among various factors. These factors can be categorised as patient related, environment/illness related or treatment related (Velligan, et al., 2009). Patient related variables include socio-demographic factors, attitudes towards treatment and substance misuse. Illness related variables include type and severity of symptoms and insight into the illness, while treatment-related variables include the side effects of medication (Novick et al., 2010). A number of studies have reported various predictors of adherence for individuals with psychosis. Demographic factors (Kirkbride et al., 2012a), insight into the condition (Novick et al., 2015), comorbid substance misuse (Asher & Gask, 2010), and lack of social support (Mas-Expósito, Amador-Campos, Gómez-Benito, & Lalucat-Jo, 2013) are considered important factors. This study will go on to investigate each of these factors in greater detail.

Although Health Psychology has been utilised to explore adherence in various conditions, the perspective of those diagnosed anti-psychotic medication remains relatively unexplored by Health Psychologists. There are various factors that may have influenced this. The unique nature of psychosis and schizophrenic illness, obfuscates concepts of illness perceptions, decision making and engagement with health

care professionals. There are occasions when patients may be considered to be a risk to themselves or others, and may require formal admission to hospital under the Mental Health Act (1983). Working with patients with the condition is often more associated with clinical psychologists. However, it is Health Psychologists who are ideally placed to investigate adherence, using well-established techniques to ensure that the autonomy of the patient is respected. The purpose of this study is to explore potential determinants of adherence to anti-psychotic medication in greater detail whilst applying the science of Health Psychology to the unique characteristics of adherence in psychosis.

CHAPTER 2.

Demographic factors and adherence.

To many, psychosis may often feel like a distant, unfamiliar condition. The stigmatisation of the illness and the way in which individuals diagnosed with the condition had historically been segregated from the rest of society, has led to some of the general public being unfamiliar with the prevalence of the disorder (Haddad et al., 2014). Indeed, some people may feel that they have not encountered or known anyone that is dealing with mental illness and can be unaware that someone they know is dealing with the condition. At face value a 1.1% incidence rate may give the impression of a statistically small figure. However, the prevalence rate for schizophrenia alone is twice as high as Alzheimer's which is often considered to be a more recognised condition (Popp et al., 2014). According to the WHO statistics, schizophrenia is diagnosed five times as often as multiple sclerosis and six times as often as insulin-dependent diabetes (WHO 2006).

2.1 Sociological, Economical & Biomedical Factors

Despite the relatively low incident rate for psychotic illness, the prevalence rates are persistently high (McGrath et al., 2004). The incidence rate for Schizophrenia is reported to be 1.1% of the population over the age of eighteen (Torrey, 2006). The average age of onset is eighteen in males and twenty-five in females (Torrey, 2006).

A comprehensive systematic review of rates indicated that when compared with females, males are moderately more likely to be diagnosed with the condition (McGrath et al., 2004). Males are also reported to experience more “negative” symptoms of psychosis, have a lower chance of making a full recovery and display worse outcomes when compared statistically with females (McGrath et al., 2004). The illness occurs throughout the world in all societies regardless of ethnicity, gender, class, religion or culture. However, although incidence levels remain relatively consistent, there is some reported variance in rates amongst different groups of people (Saha, Chant, Welham, & McGrath, 2005). New episodes are more likely to be reported in Black and other minority ethnic communities (Kirkbride et al., 2012a). Research has indicated that inner-city areas with high rates of poverty experience higher rates of schizophrenia (March et al., 2008). In a 2012 study of participants across several ethnically diverse boroughs of London, Kirkbride (Kirkbride et al., 2012a) looked to explore the reasons why urban communities have elevated rates of psychotic disorders. The research was supported by the Wellcome Trust and the National Institute for Health Research (NIHR). Results indicated that rates of schizophrenia and similar disorders showed variance after controlling for age, ethnicity, gender and social class. Findings highlighted the effects of complex societal factors that underlie the onset of mental health disorders and proposed that the risk of psychotic illness could be predicted by three environmental factors; increased population density, increased deprivation (relating to income, education, employment and crime) and increased inequality (disparities between the rich and poor). The study drew attention to the way that the socio-economic environment could impact on psychotic illness and its recovery. However, although links between social inequality and psychosis have

been explored, there is relatively little research into the impact of social inequality on adherence to anti-psychotic medication.

Previous research has indicated that health outcomes are optimised when societies are more equal (Kirkbride, Stubbins, & Jones 2012b), leading to an expectation that there may be demographic differences in adherence to medication regimes. This relates to the health inequalities that currently exist within those suffering from psychosis (Cheng et al., 2010). According to 2012 figures released by the Schizophrenia Commission (2012), individuals with serious psychiatric illnesses such as schizophrenia are on average twice as likely to develop diabetes, three times more likely to develop hypertension, four times as likely to die from coronary heart disease and ten times more likely to die from a respiratory illness. Overall, individuals with serious mental health illnesses such as schizophrenia, die 20 years earlier when compared with the general population (March et al., 2008). Figures have indicated that, of adults diagnosed with schizophrenia only 28% live independently, while 25% live with a family member, 20% live in Supported Housing, 10% live in nursing homes, 6% live in hospitals, 6% live in jails or prisons and around 6% are homeless or live in shelters (Torrey, 2006). This is significant as the majority of previous research has explored concepts in hospital settings, whereas investigating adherence in the community would be more relevant, as this is the setting in which individuals are expected to self-medicate rather than have their medication administered or monitored by staff.

There is relatively little research focus on relationships between socio-demographic factors and adherence to anti-psychotics. A study (Tsang, Fung & Corrigan, 2009)

looked at medication compliance in relation to self-stigma, insight, attitudes towards medication, and sociodemographic status in eighty-six Chinese adults diagnosed with Schizophrenia. Results identified insight as a significant predictor of adherence but also indicated that while living alone was associated with non-adherence, living in a supported environment was associated with higher levels of adherence. Previous research has proposed that socio-demographic factors including gender, age, financial status, education, marital status etc. correlate with adherence to anti-psychotic medication (Fenton, Blyler, & Heinssen, 1997; Fleischhacker, Oehl, & Hummer, 2003; Pinikahana, 2005). However, the results of correlations carried out by these studies have been inconclusive (Tsang et al., 2009). Despite these results, it is acknowledged that the socio-demographic background of an individual has some level of impact upon their level of adherence (Tsang et al., 2009). Thus, although the impact of demographic factors in psychosis has been highlighted, there is a scarcity of studies that have explored demographic concepts and their impact on adherence to anti-psychotic medication extensively. The majority of previous studies were cross-sectional and there are no studies looking at the effects of demographic characteristics on adherence over time. The current research will attempt to investigate the socio-demographic impact upon adherence in further detail.

CHAPTER 3.

Illicit substance use and adherence.

Illicit substance use amongst individuals suffering a mental health condition is prominent and considered a prevalent clinical concern. A substantial body of research has denoted that in comparison to the general population, people with severe mental health conditions such as schizophrenia are at a heightened risk of suffering from a substance use disorder (Asher & Gask, 2010; Bahorik Newhill, Queen, & Eack, 2014; Margolese, Malchy, Negrete, Tempier, & Gill, 2004; Fowler, Carr, Carter, & Lewin, 1998).

3.1 Prevalence of dual diagnosis in psychosis.

The co-occurrence of a mental health and an addictive disorder referred to as a “dual diagnosis” is frequent, with a lifetime comorbidity prevalence rate reportedly being 59% (Fowler et al., 1998). A comprehensive meta-analysis reported that around 1 in 4 individuals diagnosed with schizophrenia suffered from a cannabis use disorder, which is over five times greater than the rate amongst the general population (Asher & Gask, 2010). Alcohol dependence, nicotine use and psychostimulant misuse rates are all high in individuals suffering from a psychotic disorder, with the most commonly used psychostimulants being cocaine and cannabis (Akvardar et al., 2004). Increased drug use amongst patients has been linked to earlier onset of the disorder, increased rates of relapse, rehospitalisation, homelessness, violence, HIV infection,

legal issues, non-adherence to medication, suicide and other unfavourable outcomes (Asher & Gask, 2010; Akvardar et. al, 2004). However, these studies have used a variety of measures to explore drug use, rather than a measure specifically validated to explore drug use amongst individuals diagnosed with psychosis. Furthermore, a comprehensive review by Angermeyer (2000) suggested that a dual diagnosis is often reported to result in increased management issues from a clinical perspective with increased levels of aggression, violence and non-adherence to medication. The rates of criminal activity in Single Diagnosis patients were reported to be 13.7%, compared to 40.1% in Dual Diagnosis patients. The impact of a Dual Diagnosis is vast and may have a profound effect. Dual Diagnosis patients were reported to commit more violent crimes, and are allegedly seventeen times more likely to commit homicide than the general public. Although the prevalence of drug use and its effect on the course of psychotic illness has been widely researched, the precise mechanisms as to why this occurs remain subject to debate. Therefore, research into the impact of drug use on treatment and adherence levels to anti-psychotic medication is of high priority.

3.2 Causality.

Some individuals diagnosed with psychosis have reported using street drugs in an effort to “self-medicate” their condition and thus avoid taking their prescribed medication (Margolese et al., 2004). According to recent information, developed with the help of researchers who work at the Institute of Psychiatry Psychology & Neurosci-

ence (King's College London) and mental health professionals working at South London and Maudsley NHS Foundation Trust, some people who have a diagnosis of psychosis have reported using illicit drugs to help cope with some of the symptoms of their illness. Due to the legal implications involved this can be a highly contentious area of enquiry. It also gives rise to the debate surrounding the direction of causality between drug use and psychosis. While there is general agreement of an association between psychosis and drug use, the direction of causality remains a divisive topic. In a comprehensive 2001 literature review, Cantor-Graae, Nordström and McNeil, reported that cannabis use had predated the onset of psychotic symptoms in several studies but not in others. There was also no consensus on whether substance use impacted the age of onset for psychosis. The effect of substance use on the medical evolution of psychosis also remained subject to debate. Some of the included studies were unable to identify a relationship between substance use and changes in symptoms (Cantor-Graae et al., 2001). Other findings included greater premorbid adjustment, higher rates of marital and employment status, less brain structural abnormalities and fewer hospital admissions (Cantor-Graae et al., 2001). This has led to the view that patients who habitually use illicit substances may have a less severe form of psychosis and greater social skills, yet relatively few studies have investigated the long-term relationship of substance use on non-adherence to anti-psychotic medication.

Conversely, other studies indicate that substance use is closely associated with both non-adherence and relapse. Research suggests that patients with schizophrenia who use psychostimulants are hospitalised at twice the rate of patients who do not, with greater cannabis usage having a significant relationship with relapse rates (Van

Dorn, Desmaris, Young, Sellers, & Swartz, 2012). Alcohol dependence was linked with an increased hospital duration of twice as long, with even negligible alcohol use reported to be a predictor of rehospitalisation (Angermeyer, 2000). Substance use has been indicated as having a relationship with relapse, rehospitalisation, non-adherence to treatment, criminality and suicide (Cantor-Graae et al., 2001). However, the effects of illicit drug use to adherence to anti-psychotic medication are still unclear.

3.3 Transnational variations.

The majority of previous research into drug use in mental health populations originates from the United States and Europe, with the majority of data obtained from North America, the UK and Germany. Figures from other areas particularly developing countries are inadequately represented. In the United States around 70% of individuals diagnosed with psychosis use nicotine, 45-60% are alcohol dependent, and 31-42% use cannabis. Whereas the rates for cannabis dependence is reported to be 27% in France, 18.7% in England and 5-13% in Germany (Margolese et al., 2004). The rate for cocaine use amongst people diagnosed with schizophrenia is reported to be 15-50% in the United States, 1.5% in France and 1% in Australia, in the UK the rate of stimulant use including both cocaine and amphetamines is reported to be 8.7% (Margolese et al., 2004). The fact that these rates vary so significantly, highlights the need for additional global and local information regarding the degree, issues, impact and prevalence of drug use in assorted communities. Studies from 1990 to 2000 looking at schizophrenia, schizoaffective disorder and substance misuse

with a sample size of over thirty participants were reviewed (Cantor-Graae et al., 2001). The review did not distinguish between substance dependence or abuse. However, it did exclude studies if a defining criterion of abuse or dependence was not comprehensively quantified. The authors reported that prevalence rates altered according to the population of the study and the process used to define abuse. Rates of abuse ranged between 40 to 60%. Research that included only one technique of determining abuse tended to report lower rates than research that used more than one method. Comorbidity rates tended to be higher in samples obtained from clinical settings when compared with outpatients. Results indicated that in Australia substance use rates were particularly high amongst outpatients underlining that drug use was not just prevalent in Europe and North America.

3.4 Explanations for prevalence.

At present, there appears to be very little consensus as to the reasons for the prevalence of drug use in people with psychosis. Some research appears to suggest use can be linked to a form of self-medication as certain substances have the potential to alleviate or target certain symptoms (Margolese et al., 2004). Other research suggests that the choice of a specific substance is principally dependent on obtainability and affordability (Cantor-Graae et al., 2001). What is widely accepted is that different substances affect psychosis in different ways. Cannabis use has been known to cause anxiety, hallucinations, and paranoia (Akvardar et al., 2004). Nicotine has been associated with an improvement in negative symptoms and auditory data pro-

cessing, as well as diminishing the unwanted side effects of anti-psychotic medication. However, there are complex issues surrounding the effect of nicotine on the impact of anti-psychotic medication, particularly clozapine (Bahorik et al., 2014). Patients have reported attempting to use cocaine as a way of attenuating feelings of depression as cocaine use has been reported to lessen both positive and negative symptoms of schizophrenia (Akvardar et al., 2004).

There remains a lack of empirical evidence surrounding the reasons for the prevalence of illicit substance use and a dearth of studies that have explored the impact of illicit substance upon adherence to anti-psychotic medication. This study will attempt to investigate these concepts in greater detail. It will investigate the effects of drug use on adherence longitudinally and will explore the effects of drug use in comparison with other potential determinants of adherence, in order to view the significance of drug use compared to other factors.

CHAPTER 4. Side Effects and Adherence.

Overwhelming evidence has highlighted the efficacy of anti-psychotic medication in treating the symptoms of psychosis and bringing about improvements in the course and outcome of the condition (Zygmunt, Olfson, Boyer, & Mechanic 2002). A meta-analysis of 65 randomised control trials reported that patients treated with anti-psychotic medication displayed significantly lowered relapse rates, were less likely to be admitted to hospital or drop out of trials for any other reason (Haddad et al., 2014). However, anti-psychotic medications are multifarious in their actions and have also been associated with a range of side effects. Around 75% of individuals prescribed anti-psychotics experience side effects (Coffey, 1999). The nature, severity and extent of these side effects vary widely among individuals but some are extremely severe (McCann et al., 2009). Traditional anti-psychotic medications, in particular, have been associated with a variety of unwanted side effects. Newer atypical anti-psychotic medications were considered to lessen the array of side effects but in some cases, the side effects associated with their use are equally debilitating and even life threatening (Coffey, 1999).

4.1 Typical anti-psychotics.

Increased Health Psychology research may potentially be useful helping us understand the high rates of non-adherence in psychosis due to the unique nature of anti-psychotic treatment. Anti-psychotic medication is not always completely effective and the complex side-effects of these medications, can increase patients' concerns regarding their treatment. Traditional anti-psychotic medication was first developed

in the mid-1950s, and quickly became the treatment of choice for psychosis. They are often referred to as 'typical' or 'first-generation' anti-psychotics. Although there are many different types of typical anti-psychotics they all work in a similar way by blocking the action of dopamine receptors in the brain, some more strongly than others (Coffey, 1999). Symptoms of psychosis often get divided into "positive and negative" symptoms. Positive symptoms refer to variations in behaviour or thoughts, including hallucinations or delusions. While negative symptoms refer to withdrawal or lack of function, such as appearing emotionless and flat. Typical anti-psychotics are reportedly efficacious in treating "positive" symptoms of psychosis such as visual and auditory hallucinations. However, there are also some drawbacks associated with their use. They are ineffective at reducing the "negative" symptoms of psychosis such as social withdrawal, unemotionality or apathy. They are ineffective at reducing any symptoms in around 30% of those treated (Zygmunt et al., 2002), and for a large section of patients whose symptoms are reduced, many will go on to experience side effects which can impact adherence to the medication.

The most common form of side effects of typical anti-psychotics are referred to as "extrapyramidal side effects". Extrapyramidal side effects are a group of symptoms relating to motor control, coordination and involuntary movements. Extrapyramidal side effects can include akathisia - which manifests in a sensation of restlessness and can result in rocking and pacing up and down, tardive dyskinesia - which involves uncontrollable facial movements, dystonia - which causes muscles to involuntarily contract and contort leading to unnatural and painful movements and positioning and Parkinsonism - the same symptoms as someone with Parkinson's disease, including slower thought processes and movements, tremors, rigid muscles, difficulty speaking

and facial stiffness (Wolters, Knegtering, Van den Bosch, & Wiersma, 2009). Other common side effects of typical anti-psychotics include weight gain, photosensitivity, sedation, blurred vision, dizziness, constipation, sexual dysfunction (reduced libido or impotence), agranulocytosis (deficiency in a type of white blood cells that increases vulnerability to infections) and neuroleptic malignant syndrome and others (Coffey, 1999).

4.2 Atypical anti-psychotics.

Concerns regarding the high number of side effects of typical anti-psychotics resulted in a search for alternatives and led to the development of “atypical” or second generation anti-psychotics, which were generally thought to have reduced extrapyramidal side effects. The introduction of new atypical anti-psychotics was expected to herald a new era of improved outcomes for those suffering from psychosis. It was hoped that they would be associated with fewer extrapyramidal side effects, enhanced clinical efficacy and would lead to a marked improvement in rates of adherence to medication (Leucht, Pitschel-Walz, Abraham, & Kissling, 1999). They work on different chemical messengers in the brain and have a lower affinity for the D2 dopamine receptors but a higher affinity for D4 dopamine receptors, than typical anti-psychotics and also have an effect on serotonergic receptors (Coffey, 1999). Studies have indicated that atypical anti-psychotics are also more effective in dealing with the negative symptoms of psychosis (Tsang, et al., 2009). Clozapine is often referred to as the primary atypical anti-psychotic but was actually developed in 1959. It showed efficacy as being extremely effective for treatment-resistant psychosis, treatment of negative symptoms, reduced anticholinergic effects, reduced extrapyramidal

side effects, greater clinical efficacy and improved outcomes (Leucht et al., 1999). However, the sale of clozapine was discontinued shortly after its introduction due to concerns over its potentially fatal neutropenic side effects. It was later reintroduced with strict safeguards and guidelines involving regular white blood cell checks (and is now discontinued if these checks are abnormal), it is also associated with a range of other side effects (Coffey, 1999). Although other atypical anti-psychotics reduce extrapyramidal side effects commonly caused by typical anti-psychotics, these symptoms can and do occur with any type of anti-psychotic medication (Wolters et al., 2009). Antidepressants and other medications can sometimes cause extrapyramidal side effects as well. Other side effects of atypical anti-psychotics include sedation, excessive weight gain, increased likelihood of developing diabetes, postural hypotension, sexual dysfunction (reduced libido or impotence), excessive salivation and convulsions. Some can affect blood pressure and cause dizziness, while in high dose long term use can also cause extrapyramidal side effects (Coffey, 1999).

4.3 Symptoms versus sequelae.

The treatment of psychosis can be viewed as a trade between symptoms and sequelae. Some side effects may desist if medication is discontinued. However, extrapyramidal side effects can continue for an indefinite period and some may experience movement disorders for life after a course of treatment. Clinical concerns regarding extrapyramidal side effects are pronounced, as socially debilitating side effects can lead to enhanced social withdrawal. Around 75% of patients experience extrapyramidal side effects and clinical literature appears to ascribe this as a key concern, yet there is no clear evidence that patients view it as such (Coffey, 1999).

Atypical anti-psychotics have fewer side effects but some of these can be extremely debilitating. Atypical anti-psychotics results in a higher rate of sexual dysfunction. There has been negligible research into this aspect of side effects and it is often not mentioned in clinical practice but there is evidence to suggest that patients themselves rate this as the most severe side effect and it therefore has a negative impact on adherence (McCann et al., 2009). A community-based study reported that 50% of patients reported experiencing side effects which were not rated as severe, but the cumulative effect of experiencing a variety of different side effects raised the severity considerably. It was also noted that during initial treatment patients had difficulty differentiating side effects from the symptoms of their condition (McCann et al., 2009).

The consequences of side effects to anti-psychotic medication can impact upon physical health and personal relationships, destabilise wellbeing, affect morbidity and mortality and necessitate the requirement of regular medical supervision (Wolters et al., 2009). Despite this, the main concern is often that the severity of side effects could lead people to discontinue adherence to anti-psychotic medication (McCann et al., 2009). Although newer atypical anti-psychotics are associated with clinical advantages such as reduced side effects and increased tolerability, non-adherence rates have remained high (Remington et al., 2007). For individuals diagnosed with psychosis, relatively little is known about their perceptions of the severity of their condition and their beliefs around effectiveness of the treatment and how those beliefs influence their adherence to medication. It is imperative that measures used to assess these concepts address all aspects of side-effects to anti-psychotic medication as perceived by those prescribed them. Furthermore, there is a paucity

of research exploring these concepts over time. Thus, the complex relationship between adherence to anti-psychotic medication and side effects precepts greater longitudinal exploration.

CHAPTER 5. Social support and adherence.

Social support is conceptualised as an individual having a person or group of people who are available to them, on whom they can rely and who let them know that they are cared for, valued and loved (Sarason, Levine, Basham, & Sarason, 1983). It refers to the sustenance provided by a support network, such a network can often involve friends and family but is not restricted to just them (Mas-Expósito et al., 2013). Social networks comprise the quality, quantity and strength of relationships and the impact, support and structure of these relationships on quality of life (Macdonald, Hayes, & Baglioni, 2000). Robust social support is formed through permanency, reciprocity, positivity and regular interaction. It can include financial, emotional, advisory and informational support and companionship. A strong social support network is consistently associated with improving outcomes across a wide range of diverse illnesses and conditions, including individuals suffering from psychosis (Macdonald et al., 2000; Norman et al., 2005). Yet, research indicates that individuals with severe mental illnesses are more likely to have lowered social support and smaller social networks, with limited access to support other than that provided by mental health services. These findings go on to highlight associations between the reduced levels of social support in individuals suffering from psychosis and increases in psychiatric symptoms, relapse, rehospitalisation and lowered levels of self-esteem and quality of life. Furthermore, higher levels of social support are considered a crucial component of treatment and recovery (Mas-Expósito et al., 2013).

5.1 Impact of social support upon adherence.

The relationship between social support and adherence has received considerable research attention in Health Psychology. While research into the impact upon adherence to anti-psychotic has remained relatively unexplored, there is substantial empirical evidence for the association of social support with adherence in numerous other conditions. Meta-analyses performed following a comprehensive literature review covering 122 studies, between the years of 1948 to 2001, correlated structural or functional social support with adherence to medication, revealed a significant relationship between adherence and practical, emotional, and one-dimensional social support. There were also associations with family cohesiveness and conflict, marital status, and living arrangements of adults (DiMatteo, 2004). Social support has been purported to impact upon adherence in a range of conditions. A study exploring Social Support and Adherence for individuals diagnosed with Hepatitis C found that social support had a significant impact upon adherence. Findings revealed that while receiving treatment, individuals experience both supportive and unsupportive reactions from family, friends and healthcare providers. Supportive reactions were found to enhance adherence while unsupportive reactions were associated with reduced adherence to treatment. The authors went on to argue that in order to support treatment adherence, healthcare professionals should assess sources of support experienced by patients during treatment. When a supportive network is not in place, patients should be encouraged to attend a support group or seek counselling, while exercising empathy and caring to support adherence during treatment (Phillips & Barnes, 2016). Similarly, research into weight loss has found social support to be a significant factor in adherence (Marquez et al., 2016).

The association between social support and health outcomes has received a substantial amount of devotion in Health Psychology and behavioural medicine research. Social support is reported to guide and enhance the capacity to adjust to and live with illness and it is believed that the relationship between social support and health may be facilitated by adherence (Dunbar-Jacob & Schlenk, 2001). Backing and assistance from a support network of friends and family has been associated with enhancing patient adherence by heightening optimism and self-esteem, cushioning the stresses of being ill, reducing depression, improving health-related behaviour and providing practical assistance (DiMatteo, 2004). Although the importance of social support upon adherence has been demonstrated in numerous conditions including psychosis, studies have yet to explore this effect longitudinally for those diagnosed with psychosis.

5.2 Community treatment in psychosis.

In line with the introduction of anti-psychotic medication there have been substantial changes in the standards and delivery of psychiatric care, resulting in an increasing awareness of the importance and impact of adequate social support. Although the importance of social support in relation to adherence has been clearly established, there is relatively little information regarding the impact of social support on adherence within individuals with psychosis.

Social Support is however acknowledged to impact upon mental health and has a role in both mental illness prevention and recovery. Research has stressed that it is a key influence upon the perceived severity of symptoms, adaptations and health

outcomes amongst patients diagnosed with schizophrenia (Hamaideh, Al-Magaireh, Abu-Farsakh, & Al-Omari, 2014). It is considered a determinant in advancing recovery, can positively affect both physical and mental health and perhaps most significantly, high levels of social support is purported to act as a defensive shield that can positively enhance the quality of life of people with psychosis while decreasing the severity of their symptoms (Mas-Expósito et al., 2013). Unfortunately, many individuals with psychosis often suffer from social dysfunction and their social relationships and networks are reportedly reduced (Macdonald et al., 2000). Yet although the size of the network is reportedly reduced that may not necessarily reflect upon the level of support. A smaller social network may not affect the level of support that these individuals receive. However, in research social support is largely represented by the size of the network with some evidence suggesting that reduced networks equate with a deficiency of close relationships (Norman et al., 2005). The terms social support and social networks are subjective and multidimensional and thus difficult to quantify and measure. Research into the phenomenon has utilised a variety of measures in an attempt to explore these concepts in mental health populations. Investigating these methods to ensure they are robust may offer additional insight into adherence. Although the impact of social support upon mental health is recognised, its relationship with adherence remains largely unexplored. The measures used in this study have been validated as appropriate for the assessment of perceived social support in patients diagnosed with psychosis.

5.3 Onset of psychotic symptoms & duration of untreated psychosis.

A recent area of research into the effects of social support on psychosis is with regard to its predictive capacity on symptom outcomes and hospitalisation rates. The investigation of prognostic elements has led to increased awareness in the duration of untreated psychosis and its associations with a lack of social support. The duration of untreated psychosis, refers to the interval between the onset of psychotic symptoms and the commencement of appropriate treatment, (Norman et al., 2005). Research indicates that there are often substantial delays in the duration of untreated psychosis for individuals with schizophrenia and delays are correlated with added severity of symptoms and long-term outcomes (Mas-Expósito et al., 2013). The duration of untreated psychosis is reported to impact upon health outcomes, as comprehensive meta-analyses suggest that it has a link with symptomatic and functional outcomes (Marshall et al., 2005). It has been reported that individuals with enhanced social support pursue treatment for psychosis earlier (Norman et al., 2005).

5.4 Cultural variations in social support.

Relatively little research has explored how different cultures impact upon social support for individuals suffering from psychosis. Social support intrinsically involves relationships among individuals and groups of individuals. People from different cultural upbringings may view and be affected by social support differently and their relationship patterns are best understood within the context of culturally specific

structures (Kim, Sherman, & Taylor, 2008). This in turn should be reflected in the measures utilised to assess support and the development of culturally appropriate care (Cheng, Tu, & Yang, 2016). Research exploring social support across various societies has identified consistent cultural differences in people's inclination to utilise social support for dealing with stressors. Cultural differences affect the way in which individuals view themselves, relationships with others and their sense of self-esteem (Cheng et al., 2016).

These cultural differences may impact upon how people view, seek and accept support within their community, with people in individualistic cultures more likely to seek social support (Kim et al., 2008). Thus, in Western culture, where society is often considered more disparate and social support tends to be viewed in terms of the size of the individual's social network, individuals diagnosed with psychosis who have superior social skills may be more able to develop a larger social network, whereas individuals with a more severe and enduring form of psychosis may have less social skills and their networks may be smaller. Conversely, in more collectivist cultures, including parts of Asia, society is often considered more interdependent, and individuals viewed as connected and bound to a group, with group objectives seen as more relevant than personal needs (Kim et al., 2008).

There is a dearth of empirical studies that have explored concepts of social support upon adherence to anti-psychotic treatment utilising measures that are validated for use amongst individuals diagnosed with psychosis. There also remains a lack of research that have scrutinised these concepts longitudinally. This thesis will explore

the impact of social support upon adherence to anti-psychotic medication in light of the unique characteristics of adherence in psychosis.

CHAPTER 6. Illness perceptions and adherence.

Poor insight into the condition is considered a core characteristic in psychosis, with between 57-98% of individuals diagnosed with schizophrenia unaware of having a mental disorder (Lehrer & Lorenz, 2014). Insight into illness has been defined as the acceptance of the clinician's illness model by the patient (Beck et al., 2011).

6.1 Illness insight.

As poor illness insight is a common feature in psychosis, it has been argued that this lack of insight can lead to negative attitudes towards treatment. Lowered insight has been linked with lower self-esteem, hopelessness, depression and increased internalisation of stigma (Lincoln, Lullmann, & Rief, 2007). Much of the research into predictors of insight has utilised samples of chronic patients from in-patient settings, but interest has increased in exploring correlates and predictors of insight amongst individuals who have been recently experiencing symptoms. Research into first episode psychosis indicates that insight is associated with advanced negative and disorganised symptoms, severe depression, severe unusual thought content and increased severity of overall symptoms (Ayesa-Arriola et al., 2011). Investigations into cognitive insight identified an indiscriminate dysfunction of the neural networks that undertake decision-making tasks, with a reduced cognitive insight linked to impaired insight. Cognitive insight was also reported to have connections to memory (predominantly working memory) and verbal learning (Ayesa-Arriola et al., 2011).

The absence of illness insight is purported to be a key factor in medication non-adherence (Novick et al., 2015). An increasing body of research has been devoted to exploring the foundations and effects fundamental to the lack of insight in psychosis. It is believed that enhancing knowledge and awareness of psychotic illness and its treatment increases adherence to medication, yet research evidence is varied. Investigations of the scientific and neurocognitive associations of insight have provided capricious results (Ayesa-Arriola et al., 2011). A contemporary meta-analysis suggested that psychoeducation had no significant effect upon adherence (Lincoln et al., 2007). The results of longitudinal studies exploring insight on medication adherence have been inconclusive which has intensified reservations of its predictive capacity (Beck et al., 2011).

6.2 Theoretical perspectives on illness perceptions.

Health Psychology has provided valuable frameworks to explore concepts of illness perception and insight. Illness Perception refers to a set of beliefs concerning how individuals make sense of their health status (Mak, Chong, & Wong, 2014). The notion of illness perception has been used to explain how a representation of one's illness is created as a mechanism to make sense of one's condition and create adequate reactions. For patients with mental health issues, the attributions and perceptions of their illness could potentially either hasten or defer pursuing treatment, which in turn impacts upon the conduits of clinical care and future prospects. Psychotic episodes would thus inform the patient's beliefs regarding recognising their status and the associated personal and social consequences, irrespective of whether the

illness itself is acknowledged by the patient or not (Gómez-de-Regil, Kwapil, & Barantes-Vidal, 2014). It is common to find partial awareness among mental health patients who refer to symptoms using their own terminology. Illness perception comprises of cognitive and emotional representations and does not require recognition of the condition as an illness (Moss-Morris et al., 2002). One of the more influential illness perception models is Leventhal's Self-Regulation Model of Health and Illness Behaviour (Leventhal, Leventhal, & Contrada, 1998; Leventhal, Leventhal, & Cameron, 2001). The Self-Regulation Model interprets illness perceptions as a key component of determining how people understand and manage threats to their health (Fischer et al., 2010).

Alongside The Theory of Planned Behaviour (Ajzen, 1985), The Self-Regulation Model (variously referred to as Leventhal's Theory, The Common Sense Model, the Common-Sense Model of Self-Regulation of Health and Illness etc.) have both been frequently utilised as health-related decision-making frameworks by Health Psychologists. The Theory of Planned Behaviour originates from rational models of decision-making, and has been extensively used to forecast and explore a variety of health behaviours (Sivell, Edwards, Elwyn, & Manstead, 2011). However, the Theory of Planned Behaviour has faced increasing challenges in recent times (Ogden, 2015). Criticisms include that it is not falsifiable, that it creates rather than measure cognitions and that its constructs can be tautological (Ogden, 2003). While the Theory of Planned Behaviour attempts to forecast patient decisions, the Self-Regulation Model scrutinises how the wider representation of a condition helps the patient deal with that condition. It offers a framework explaining how patients make sense of their condition and their perceptions of accessible treatments, assigning more importance

on emotional and coping responses when rationalising illness-related behaviour (Wearden & Peters, 2008). The Self-Regulation Model is theoretically derived and purports that people create their own representations of their condition that aids making sense of their experience and facilitates coping. It outlines the corresponding cognitive and emotional processes that intermingle in the way an individual copes with and adjusts to their condition, in the same manner that a health risk generates both a cognitive representation of the threat and a parallel requirement for processes to cope with the risk (Snell, Hay-Smith, Surgenor, & Siegert, 2013).

The Self-Regulation Model identifies the dynamics involved when patients process information that help them develop lay perceptions of the illness (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 2001; Leventhal, Weinman, Leventhal, & Phillips, 2008). These perceptions inform coping behaviours and outcomes. It theorises that lay perceptions develop in three stages, namely; interpretation of the problem (whereby cognitive representations, or an abstract model of the illness are developed by the patient), action plan / coping stage (during which the patient identifies and cultivates appropriate coping strategies) and the appraisal stage (where patients appraise their strategies to decide whether to continue with their current coping strategy or cultivate an alternative). These stages endure until the coping strategies implemented are viewed as being effective and a state of equilibrium is reached (Sivel et al., 2011). Originally, the self-regulation model identified five cognitive components of illness representations (Leventhal et al., 1984). These are identity (which refers to the illness label used to describe the condition and associated symptoms), causal attributions (the individual's perception of what caused the onset of the illness), expected consequences (the anticipated

effects and outcome of the illness), perceptions of controllability/curability (the extent to which individuals believe they will be able to recover from or control the illness through treatment) and timeline perceptions (the length of time that the individual believes their condition will last) (Snell et al., 2013). Subsequently, three further cognitive dimensions were added to the model, these components addressed emotional representations (emotional perceptions related to the illness), cyclical timeline beliefs (perceptions related to variations in symptoms and unpredictability of the condition), and coherence (the extent to which the individual coherently understands their condition) (Moss-Morris et al., 2002). These components are not independent of each other and can often be connected or interrelated. Illness representations can be affected by a variety of elements, including past experience, experiences related by an acquaintance who underwent treatment, knowing someone diagnosed with the illness as well as information provided by friends, relatives, the media and health care professionals (Sivell et al., 2011).

Health Psychology offers robust theories and models to explain, describe and predict health behaviour and the Self-Regulation Model is appealing to Health Psychologists as it theorises that people are problem solvers who take an active role in the management of their own health (Wearden & Peters, 2008). The self-regulation model has been successfully employed by researchers in attempts to further understandings of health outcomes in an assortment of conditions including chronic fatigue syndrome (Wearden & Peters, 2008), chronic pain (Snell et al., 2013), cardiovascular disease (Sivell et al., 2011), fibromyalgia (Miró et al., 2011), cancer (Dillard, Ferrer, Ubel, & Fagerlin, 2012) and traumatic brain injury (Hou et al., 2012), amongst others.

6.3 Impact of stigma upon perceptions of illness, coping strategies & adherence in psychosis.

Although illness perceptions and the Self-Regulatory Model have been utilised to assess adherence in a variety of health conditions, the perspective of individuals diagnosed with psychosis has remained relatively unexplored. Conversely, investigations into the causes and consequences of the lack of insight in schizophrenia have become increasingly prominent. Mental illness is a highly stigmatised condition, and individuals who have been diagnosed with the condition have reported being the subject of both stigma and discrimination. Research has highlighted that the stigma experienced by individuals with a mental health illness interferes with recovery efforts including adherence (Sarkin et al., 2015). Stigma has been described as biased behaviours, negatively predisposed attitudes and prejudiced social structures, that occur when a substantial collection of society validates negative attitudes towards a subgroup (Corrigan, 2000). Stigma has multifaceted and confounding effects on people's welfare and societal circumstances affecting the public's perceptual, emotive, and behavioural responses towards the stigmatised illness and those diagnosed with it (Angermeyer, 2000). Stigma has been acknowledged as a key facilitator of psychological and behavioural symptoms, which can have far reaching impact upon the individual and society as a whole (Mak et al., 2014). The stigma experienced by individuals diagnosed with a mental illness leads to an increased reluctance to disclose details regarding their mental health and impacts upon engagement with professionals and treatment (Sarkin et al., 2015). There is reported discrimination of individuals with mental illness in employment, housing and other social opportunities with public opposition to the setting up of rehabilitation facilities in their locality (Mak

et al., 2014). It is theorised that those diagnosed with mental health conditions often deny the illness as a coping mechanism, as a way to protect themselves from the adversity of the condition (Angermeyer, 2000). A consequence of this coping mechanism is poor engagement levels with clinicians and diminished adherence for patients diagnosed with mental illness (Sarkin, et al., 2015). This fits into the characteristics of paranoia, grandiose delusions and false beliefs, which are common features of psychotic illness (Thornley & Adams, 1998).

6.4 Importance of therapeutic relationships upon illness perceptions in Psychosis

The specialised skills required by mental health practitioners may have impacted the relative lack of research conducted by Health Psychologists on adherence to anti-psychotic medication. Research into the impact of illness insight upon therapeutic relationships has enhanced awareness of its influence. A study made up of inpatients diagnosed with schizophrenia and schizoaffective disorder suggested that poor therapeutic relationships and poor insight were correlated with low levels of adherence (Misdrahi, Petit, Blanc, Bayle, & Llorca, 2012). Studies have explored the relationship between therapeutic relationships, insight and adherence (Beck et al., 2011). However, these studies have faced limitations due to small sample size. Previous research has suggested that the main predictor of engagement levels was mainly demographic (Dunbar-Jacob & Schlenk, 2001). Yet, more recent exploration has indicated that illness beliefs have been used to predict engagement levels, with those who associated internal psychological causes to their symptoms, less likely to drop out of therapy (Marcus et al., 2014). Many of these studies have taken place within

in-patient settings. However, within these settings professionals will routinely administer medication. Therefore, research of individuals who reside in the community and self-medicate would appear advantageous when investigating adherence.

A plethora of research has reported evidence for the predictive role of patients' illness perceptions in coping responses and health outcomes (Wearden & Peters, 2008; Snell et al., 2013; Sivell et al., 2011; Gómez-de-Regil et al., 2014; Moss-Morris et al., 2002; Mak et al., 2014). Although studies in the general population have explored the effectiveness of utilising the self-regulation model in examining adherence to treatment programmes, the perspective of schizophrenia patients has remained largely unexplored. This is a key issue as findings highlight that many patients with schizophrenia are exposed to serious health risks due to non-adherence. Thus, in spite of the increasing research into the impact of illness perception upon adherence, numerous questions endure regarding its causes and impact upon people with psychosis. As yet, very few studies have investigated whether illness perceptions impact upon medication adherence amongst individuals with psychosis. With even fewer exploring these concepts longitudinally. As it is proposed that the disposition of one's self-regulation is cyclical, it would be insightful to explore whether this impact evolves over time utilising concepts provided by the self-regulation model.

CHAPTER 7. Purpose of this study, Aims, Rationale, Research Question and Hypothesis.

The present study expands upon previous research, while exploring determinants of adherence to anti-psychotic medication and relationships between any of the factors considered to possibly impact upon attitudes towards adherence. It also attempts to highlight methods that could improve these factors in a positive nature. Upon reviewing past research, it seems clear that non-adherence to anti-psychotic medication stands as one of the foremost challenges in psychiatry (Aldridge, 2011). It is linked to detrimental treatment outcomes, relapse, rehospitalisation and reduced psychosocial functioning (Weiden et al., 2004). The consequences of non-adherence can be overwhelming for patients, those close to them, society in general and the economy (Byerly et al., 2007).

Exploring ways of improving adherence is viewed as a crucial component in future research (Acosta et al., 2009; Srinivasan & Thara, 2002). The dynamics which influence adherence can be described as an interaction between various factors including patient related, environment/illness related or treatment related factors (Velligan et al., 2009). A number of review studies have reported various predictors, with increasing evidence indicating that the seeds of non-adherence are rooted in factors associated with drug use, side effects, social support, illness insight and demographic factors (Lacro et al., 2002; Masand et al., 2009; Novick et al., 2010). However, the majority of previous research has been cross-sectional, utilising participants from in-patient settings and varying, non-standardised measures. There is a

dearth of studies that have satisfactorily identified the relative significance of the various risk factors for non-adherence. Previous studies have mainly focused on one risk factor at a time and there is scant research that has explored several risk factors simultaneously in order to identify the most significant predictive factor. Many of the studies exploring adherence to anti-psychotics were retrospective, cross-sectional and conducted prior to atypical anti-psychotic medication becoming available or the development of new features such long-acting depot injections (Novick et al., 2010). Although some degree of research has looked at factors in isolation, studies utilising a longitudinal method to explore which of these factors have the greatest predictive capacity in individuals with a mental health impairment are rare. Furthermore, much of the previous research in this area appears to be limited to data collected at one particular time and to the best of my knowledge there has been no longitudinal study in the area exploring the interaction between these concepts. Adherence can vary over time and a longitudinal design comparing data obtained from participants at two time points is imperative in order to examine if adherence should be viewed as continuously disturbed rather than naturally dichotomous (Razali & Yusoff, 2014).

There is a paucity of prospective studies that have explored predictive concepts in depth and it is currently unclear as to which factors are the best long-term predictors of adherence to anti-psychotic medication. The purpose of this paper is to apply the science of Health Psychology to exploring determinants of adherence to anti-psychotic medication. It aims to further our understanding of the elements and occurrences of the issues involved, while discussing factors that could potentially enhance these issues to a positive nature. The objectives of the present study are based on

Leventhal's Self- Regulation Model. The Self-Regulation Model suggests that individual's beliefs about the causes, duration, consequences of the illness, and whether or not they have some control over the illness, influences the way the person adjusts and copes with that illness (Leventhal, 1985). Extending this model, it is argued that the way in which individuals being treated with anti-psychotic medication conceptualise their illness may be an important factor for their adherence. As multiple correlations were undertaken and to avoid type 2 error, only findings at $p < 0.01$ were considered significant. Similarly, as the analysis looks to determine if there is a relationship between variables in either direction, two-tailed tests are utilized and therefore the hypothesis is non-directional.

This study aims to explore the psychosocial, clinical and demographic factors that may potentially impact adherence in individuals with psychosis. Two main questions will be explored:

1. Are demographic characteristics, perceived levels of social support, illness perceptions, drug use and side effects at baseline associated with adherence both at baseline and 6-month follow-up
2. Which of the baseline factors examined (demographic characteristics, perceived levels of social support, illness perceptions, drug use and side effects) are the strongest determinant of adherence both at base line and 6-month follow-up?

Specifically, it is hypothesised that:

- a. Demographic characteristics such as age, employment status, marital status and educational status at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- b. Perceived levels of social support at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- c. Illness perceptions (Consequences, Illness Timeline, Personal Control, Treatment Control, Identity, Concern, Understanding and Emotional Representations) at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- d. Drug use at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- e. Side effects of antipsychotic medication at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.

SECTION 2.

METHODOLOGY & RESULTS

CHAPTER 8 Methodology

8.1 Design

This is a longitudinal questionnaire study. Data was collected at two time points. The initial stage of data collection (baseline) took place in Autumn 2015, with the second phase (T2) taking part six months later, in the Spring of 2016. Ethical Approval was sought from City, University of London's Psychological Research Ethics Committee and was granted on 12th of May 2015. Ethics Approval Code; PSYCH (P/F) 14/15 155 (Refer to Appendix).

The time scale for the second phase of data collection was set six months later as this mirrors current Care Programme Approach (CPA) meeting timescales, Community mental health teams (CMHTs), arrange a CPA meeting every six months for individuals with psychosis who are treated in the community. During these meetings, events over the previous six months are reflected upon and plans for the following six months are arranged. Knowledge of potential risk factors that could affect people within this time scale is of imperative practical use in developing interventions, approaches, strategies and planning.

8.2 Ethical considerations.

While composing the procedure, careful consideration was provided to ethical issues to ensure that the study met with BPS guidelines. The researcher obtained DBS clearance to work with the individuals involved. As the study did not involve NHS patients, NHS clinicians or NHS premises, university ethics were considered acceptable. The study was approved by the university's psychology ethics committee. Approval Code; PSYCH (P/F) 14/15 155 (Refer to Appendix A). Further to the standard considerations, the researcher ensured that none of the recruited participants were currently, nor had previously been under the clinical care of the researcher. Participants were recruited from individuals who were not subject to Sections 2, 3, 4 or 5 of the Mental Health Act (1983). Individuals can be admitted, detained and treated under different sections of the Mental Health Act, the term 'sectioned' is used to describe a compulsory admission to hospital and these sections refer to in-patient admissions. Section 2 refers to an admission for assessment. Section 3 refers to an admission for treatment, while Section 4 refers to an emergency admission. Section 5 involves being stopped from leaving hospital as a voluntary or informal patient. The reasoning for excluding individuals who were subject to these conditions was due to potential debate surrounding issues regarding informed consent. Specifically, the extent to which individual's subject to conditions of the Mental Health Act (1983) would be able to provide informed consent to participate in the study. Individuals over the age of 18 who were subject to Section 117 (after care) or a Community Treatment Order were able to take part, as these individuals would have been reviewed by their multi-disciplinary team and clinically assessed as able to reside in the community and deemed as having individual capacity under the terms of the Mental Capacity

Act (1983). They would therefore be able to provide individual consent. The researcher ensured that no form of coercion was used to encourage participation.

All participants were provided with a consent form which they were asked to read and sign. They were informed that participation in the study was entirely voluntary and that they were entitled to withdraw at any time. It was made apparent that any personal information supplied, together with the data resulting from their participation, would be recorded in an anonymous form, remain anonymised and be stored in a secure location. This encouraged participants to be honest when answering the questions, but also fulfilled the informed consent requirements. Participants were given the option of being accompanied by a key worker or any other appropriate adult. They were asked if they had fully understood what had been said and further if they would like to continue participation. Participants were also encouraged to speak to the researcher or their key worker if they had any concerns.

Participants were fully debriefed following data collection and at this point the educational value of the study outlined. Participants were able to ask questions and the researcher was able to address any questions or issues to ensure that those individuals that continued with participation were content with their involvement.

8.3 Participants.

Participants were recruited from a range of locations including community-based charities, online forums, social media, community centres, supported accommodations, sheltered accommodations and support groups. The majority of initial participants were recruited from a number of registered organisations running community based step-down accommodations providing independent group living for individuals with mental health needs in the North, North East and West London areas and the sample subsequently snowballed via word of mouth. The researcher also attended monthly service user forums at the supported care environments in order to explain the purpose of the study and recruit participants. Potential participants were given an information sheet of the study with researcher's details to get in touch if they wanted to take part. Only participants residing in the community took part. One hundred and twenty-six participants were initially recruited and consented to take part. Thirteen of the participants provided partially completed or illegible questionnaires while three participants later decided to withdraw from the study resulting in one hundred and ten individuals featuring in the first stage. All participants who took part in the initial data collection were contacted again after six months and those who remained eligible were invited to take part in the second stage. Twenty-five individuals (22.72%) dropped out from the second stage of data collection. The second stage of data collection, comprised of eighty-five individuals who were provided with the same set of questionnaires, which they were asked to complete and return to the author. The same process and procedures as during the first stage of data collection were adhered too.

Inclusion criteria

Participants were eligible for inclusion if they:

- ☐ Were currently prescribed anti-psychotic medication.
- ☐ Were aged over 18.
- ☐ Resided in the community.
- ☐ Were fully discharged and not subject to Sections 2, 3, 4 or 5 of the Mental Health Act (1983).

Exclusion criteria

Potential participants were excluded if they:

- ☐ Were having medication administered to them by others.
- ☐ Resided in a mental health ward or residential care home and not fully discharged in to the community.

8.4 Patient & Public involvement in choosing questionnaires.

The researcher has experience working within mental health settings, and has developed a staged self-medication programme. The author was therefore determined to be explicit in detailing previous experiences and circumventing any potential pre-conceived notions from his prior involvement of working within mental health. In order to avoid any form of examiner bias, it was decided to run a focus group in order to attain patient and public involvement in finalising which questionnaires to be utilised

in this research. This allowed the research to identify & employ measures that participants would potentially feel most comfortable completing, while removing any pre-determined ideas or subconscious agendas based on the researcher's experience of utilising these measures in previous professional practice.

Prior to the collection of data, the researcher had posted an invite for the focus group at a recovery club meeting, which took place at a local Community mental health group. The group was facilitated by the researcher and lasted for 90 minutes. It was attended by seven individuals. Four of these individuals were, or had previously been, prescribed anti-psychotic medication, two were carers for individuals prescribed anti-psychotic medication and one was a keyworker for an individual prescribed anti-psychotic medication. The focus group were provided with different measures which assessed factors associated with adherence and provided feedback on each one, which was then discussed with the group. Wherever possible, the researcher attempted to provide several measures for each factor and attempted to establish the process for data collection in a way that would optimise responses and participation. In total 11 questionnaires were provided (Refer to Appendix B). These included the Medication Adherence Rating Scale (MARS), the Medication Adherence Questionnaire (MAQ), the Drug Abuse Screening Test (DAST-10), the Drug Attitude Inventory (DAI), The Liverpool University Neuroleptic Side-Effect Rating Scale (LUNSERS), the Systematic Monitoring of Adverse events Related to Treatments (SMARTS), the Glasgow Anti-psychotic medication Side effect Scale (GASS), the Illness Perception Questionnaire (IPQ), the Brief Illness Perception Questionnaire (BIPQ), the Social Support Questionnaire (SSQ) and the Duke-UNC Functional

Social Support Questionnaire (FSSQ). People were also asked for their thoughts on the research in general and reasons why they would or wouldn't take part.

At this stage, the measures to be used in the study were finalised and the procedure for data collection established, based on the feedback received. Several questionnaires were rejected based on comments received. Six of the seven focus group members stated that they felt the Illness Perception Questionnaire was overly lengthy and therefore the Brief Illness Perception Questionnaire was chosen, as it was felt that this adequately addressed relevant aspects of the condition. Although three individuals also felt that the Glasgow Anti-Psychotic Side Effect Scale was time consuming, all seven individuals agreed that it adequately addressed sexual side-effects for both males and females which the other questionnaires did not, and was therefore considered to be the most suitable for use in the study. As observations included the fact that completing numerous questionnaires could negatively impact upon concentration, it was decided to keep the demographic questionnaire brief. The final questionnaires selected for use in this study are the Medication Adherence Rating Scale (MARS), the Brief Illness Perception Questionnaire (BIPQ), the Glasgow Anti-psychotic side effect scale (GASS), the Drug Abuse Screening Test (DAST-10) and the Duke-UNC Functional Social Support Scale (FSSQ).

Aspects of medication taking were discussed and it was mentioned that individuals living in mental health wards or residential care homes might be required to adhere to their medication programme as a condition of the stay. Some individuals residing in residential care would have their medication administered by staff and compliance

monitored. For others, professionals would often prompt/remind them to take medication even when the individual concerned was self-medicating. Therefore, it was decided that the study should target individuals who lived independently or in the community. It was also decided that the study should be as inclusive as possible and should focus on all individuals who were prescribed anti-psychotic medication rather than focusing on a particular condition or medication. This was because individuals often rejected terms such as “schizophrenic”, and individuals were often prescribed several types of anti-psychotic medication during the course of their treatment.

8.6 Measures.

The following assessments were administered in one session. All participants who completed the assessments and who remained legible under the inclusion criteria were invited to undertake the assessment process again twenty-four weeks later.

Outcome variable

Medication Adherence Rating Scale (MARS)

In order to assess medication adherence, this study utilised the Medication Adherence Rating Scale (Thompson, Kulkarni, & Sergejew, 2000). The MARS was developed to address perceived deficiencies of previously used adherence measures. It expanded upon widely used psychiatric research measures such as the Drug Attitude Inventory (DAI) and the Medication Adherence Questionnaire (MAQ) in an attempt to cultivate a medication adherence tool with enhanced validity, reliability and

clinical utility (Thompson et al., 2000). Upon creation, the authors assessed the measure utilising a sample of sixty-six patients the majority of whom had been diagnosed with schizophrenia and it was reported to be a reliable and valid quantifier of adherence for psychoactive medication. This has been endorsed by supplementary research with a large-scale validation study (n=277) of the MARS, which attempted to establish the psychometric properties in psychosis, reporting good internal consistency, concurrent and predictive validity (Fialko et al., 2008). The MARS is a ten item self-report measure. It consists of either “yes” or “no” answers, specifically designed to assess adherence in psychosis and takes approximately eight minutes to complete.

Once data was collected for this study, the authors assessed the scale reliability for the measures utilised by calculating the Cronbach’s alpha of each scale. Analysis revealed that The Medication Adherence Rating Scale (Cronbach’s $\alpha = .79$), had a high reliability score.

Predictor Variables

Glasgow Anti-Psychotic Side Effect Scale (GASS)

Anti-psychotic medication can cause a wide range of adverse side effects (McCann et al., 2009; Coffey, 1999). Current guidelines advise regular monitoring of side effects (National Institute for Health and Care Excellence (NICE) 2012). Numerous attempts at developing and validating a precise tool to gauge the side effects of anti-

psychotic medication have been made. As research (McCann et al., 2009) has suggested that sexual dysfunction can have an adverse impact on adherence it was important to use a measure that assessed this. This study chose to utilise a comprehensive scale which not only addressed all relevant side effects to anti-psychotic medication but had also been validated for use with individuals suffering from psychosis. Of the scales currently utilised the Glasgow Anti-Psychotic Side Effect Scale (GASS) is widely considered to be most suitable for clinical use and contains ratings of both metabolic and neuromuscular side effects. A recent validation study reported high construct validity, discriminatory power and test–retest reliability (Nystazaki, Tsapakis, Hadjulis, & Alevizopoulos, 2014). The GASS contains 21 questions for males and females (including questions related to gender specific sexual dysfunction). It utilises self-explanatory questions in everyday language, takes around five minutes to complete, and provides an organised, methodical technique of reviewing side effects to anti-psychotic medication. Following data collection for this study, the scale reliability for the GASS scale was assessed by calculating the Cronbach's alpha (Cronbach's $\alpha = .89$).

Duke–UNC Functional Social Support Questionnaire (FSSQ)

Originally developed and tested on 401 randomly selected patients, the Duke-UNC Functional Social Support Questionnaire (Broadhead, Gehlbach, DeGruy, & Kaplan, 1988), is an eight-item measure that takes approximately five minutes to complete and is a commonly used psychometric instrument to assess the social support in individuals with psychosis. It is an instrument which measures the strength of social

support networks. Responses are scored on a one to five scale. The higher the average score, the greater the perceived social support.

Test-retest reliability evaluations have reported a correlation coefficient of .6. Item-remainder correlations were used to assess internal consistency and ranged from .50 to .85. Construct validity and concurrent validity demonstrated significant correlations (Broadhead et al., 1988). Numerous studies have examined the psychometric properties of the Functional Social Support Questionnaire (FSSQ) in a wide range of populations. A recent study validated its use amongst two hundred and forty-one patients with psychosis, this study included a one year follow up and highlighted the measures reliability, validity and excellent internal consistency, concluding that the FSSQ is appropriate for the assessment of perceived social support in patients with psychosis (Mas-Expósito et al., 2013).

The Cronbach's alpha of the scale, calculated following data collection stage in this study indicated a high reliability for the Functional Social Support Questionnaire (Cronbach's $\alpha = .96$).

The Drug Abuse Screening Test (DAST -10) Questionnaire

The Drug Abuse Screening Test (DAST-10) is a 10 item brief screening tool. The test is easy to administer and can be used to assess drug use within a variety of groups (Skinner, 1982). A comprehensive literature review of articles that addressed the reliability and the validity of the DAST-10 reported that it tended to have moderate

to high levels of test–retest, validity, sensitivity, specificity and reliabilities. The review covered the years from 1982 to 2005 and concluded that the DAST provided suitable measures of reliability and validity for use as a scientific research tool within a wide scale of populations including psychiatric inpatients and outpatients. (Yudko, Lozhkina, & Fouts 2007). It assesses illicit drug use in the past 12 months, takes approximately eight minutes to complete and comprises of ten questions each requiring a yes or no response. For the present study, the reliability for the Drug Abuse Screening Test was high, (Cronbach's $\alpha = .90$).

The Brief Illness Perception Questionnaire (Brief IPQ)

The Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996) is an instrument designed to offer a quantitative assessment of the relationship between the five components of illness representation; identity, timeline, consequences, cause and control/cure as described in Leventhal's Self-Regulatory Model (Leventhal et al., 1984, 1998). It has been validated for use in studies of illness perception in patients with a wide range of conditions (Moss-Morris et al., 2002). A revised version of the IPQ measure expanded upon the original scale utilising additional items, subscales and incorporating an assessment of patients' perceptions on how well they comprehend their illness and their emotional response to the illness (Moss-Morris et al., 2002). Although comprehensive, its scale is long, and in many clinical and research situations there was a need for a shorter version, particularly when patients were very ill, when there was limited time available for assessment,

or when patients were asked to complete numerous questionnaires. In 2006, Broadbent, Petrie, Main and Weinman addressed this need with the publication of The Brief Illness Perception Questionnaire (Brief IPQ; Broadbent et al., 2006).

The Brief IPQ is a nine item self-report questionnaire. It provides a quantitative assessment of illness representations as set out in Leventhal's Self-Regulation Model, it consists of a scale designed to swiftly evaluate cognitive and emotional representations of illness. A validation study illustrated that The Brief IPQ demonstrated good test–retest reliability, validity with relevant measures and also demonstrated good predictive validity in patients undergoing psychological interventions. The scale takes approximately five minutes to complete. The validity of the Brief IPQ was further supported by its ability to distinguish between different illnesses (Broadbent et al., 2006).

In this study, the scale reliability for the Brief IPQ was measured by calculating the Cronbach's alpha following data collection. Analysis revealed that, the Brief Illness Perception Questionnaire (Cronbach's $\alpha = .749$) had high reliability.

The subscales of the Brief IPQ were constructed according to the scoring instructions (Broadbent et al., 2006). This allowed the focus to remain on the assessments of the components of illness representation described by Leventhal's Self-regulation model (Leventhal et al., 1984, 1998) within a population of patients prescribed anti-psychotics.

Demographic Questionnaire

The demographic questionnaire was a self-developed, six-item tool that recorded age, gender and ethnicity as well as relationship, education and employment status.

8.7 Procedure.

The experimenter attended recruitment venues for a period of twenty-four weeks in total. Participants were given a detailed information sheet before they consented to take part in the study. All participants were asked to read and sign a consent form and informed that participation in the study was entirely voluntary. Furthermore, upon providing the questionnaires, participants were made aware that they were entitled to withdraw at any time for any reason (in which case the data provided would be discarded). It was made apparent that any personal information supplied, together with the data resulting from their participation, would remain confidential, be recorded in an anonymous form, and be held in a secure place. If participants chose, they were accompanied by their key worker or other appropriate adults. Participants were asked if they had fully understood what had been said and if they would like to continue participation. Upon agreeing, participants moved to a quiet office area, were asked to sign the consent form and provided with the Demographic Questionnaire, the Medication Adherence Rating Scale, The Glasgow Anti-Psychotic Side Effects Scale, The Drug Abuse Screening Test-10 and the Brief Illness Perception Questionnaire.

In order to avoid confounding effects, the order in which the questionnaires were handed out was randomised. Participants were asked to take their time filling out the questions and to ask the experimenter if they had any queries (i.e. meaning of a word). Upon full completion of the questionnaires, participants were debriefed and a 'debrief form' was provided which informed participants of the nature and aim of the study. This was to ensure that participants fully understood the instructions and the conditions of the study. As the study involved questions about illegal recreational drugs, the debrief sheet emphasised that illegal drugs tend to be harmful and participants were provided information about drug effects and made aware that if participation caused any emotional distress or concern, or they required further information a list of organisations that they could contact was provided. Arrangements were made to repeat the procedure in six months' time at which point they were contacted directly by the researcher and those willing, who remained eligible were asked to complete the same process again.

8.8 Data Analysis.

Statistical Analysis was carried out using the Statistical Package for Social Science, version 24 (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp). Demographic information was gathered and descriptive statistics assessed. T-tests were conducted to explore how results varied between baseline scores and six month follow up scores. Relationships between different factors were investigated utilising Pearson's Correlations and Analysis of variance. Because this study was exploratory a standard multiple regression analysis was utilised with independent (predictor) variables entered simultaneously, as no

previous research or theoretical model could guide the choice of variables in each step. Therefore, Simultaneous Multiple Regression Analysis was used to explore the determinants of anti-psychotic medication adherence. Eleven independent variables were incorporated; drug use, social support, side effects, demographic factors and the eight components of illness perceptions (namely; consequences, timeline, personal control, treatment control, identity, concern, understanding and emotional representations), with adherence at Baseline (T1) and Six-month follow up (T2) as the dependent variable. As multiple correlations were undertaken and to avoid type 2 error, only findings at $p < 0.01$ were considered significant. Similarly, as the analysis looks to determine if there is a relationship between variables in either direction, two-tailed tests are utilised and therefore the hypothesis is non-directional.

CHAPTER 9. Results.

Research Question and Hypothesis

The objectives of the present study are based on Leventhal's Self-Regulation Model. The Self-Regulation Model suggests that individual's beliefs about the causes, duration, consequences of the illness, their identity and whether or not they have some control over the illness, influences the way the person adjusts and copes with that illness (Leventhal, 1985).

This study aims to explore factors associated with adherence in individuals with psychosis. Two main questions were explored:

- 1.** Are demographic characteristics, perceived levels of social support, illness perceptions, drug use and side effects at baseline associated with adherence both at baseline and 6-month follow-up.
- 2.** Which of the baseline factors examined (demographic characteristics, perceived levels of social support, illness perceptions, drug use and side effects) are the most significant determinants of adherence both at base line and 6-month follow-up?

Specifically, it was hypothesised that:

- a. Demographic characteristics such as age, employment status, marital status and educational status at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- b. Perceived levels of social support at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- c. Illness perceptions (Consequences, Illness Timeline, Personal Control, Treatment Control, Identity, Concern, Understanding and Emotional) at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- d. Drug use at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.
- e. Side effects of antipsychotic medication at baseline will be associated with adherence to anti-psychotic medication both at baseline and at 6-month follow-up.

A total of one hundred and ten participants were eventually included in the baseline stage of data collection, while eighty-five individuals took part in stage two of data collection at six-month follow up.

9.1 Demographic characteristics (baseline) and Dropout

Participant characteristics.

Outliers and distribution of data.

Once the data was coded and checked preliminary analyses were carried out to ensure that the assumptions of normality, linearity, homoscedasticity and multicollinearity were not violated. No univariate or multivariate outliers were removed as all scores fell within the normal range. Histograms were generated for continuous data in order to assess for normal distribution. It was noted that the DAST scores were negatively skewed. Upon further analysis, it became clear that the DAST scores appeared skewed as they had not been re-categorised as per the instructions accompanying the questionnaire and this was rectified by re-categorising scores according to the instructions. To establish homoscedasticity, Levene's test was utilised. There was no homogeneity of variance between any measures which indicated that variances were not significantly different for any of the variables.

Missing data.

The same procedures and questionnaires were used to assess the same participants with a six-month gap. To check for systematic patterns in missing data, Little's test of Missing Completely at Random (Little, 1988) was conducted and found not to be significant (Chi-square=1074.89, DF= 1053, $p=.313$), suggesting that the amount of

missing data was minor and appeared random in nature. Missing values were replaced with the mean scores of the remaining items when less than 20% of a subscale was omitted.

Demographic characteristics.

Of the one hundred and ten individuals who took part in the baseline stage of the study, seventy-three were male (66.4%) and only thirty-seven were female (33.6%). This varies from the diagnosis demographics for the condition, which tend to be moderately higher for males (McGrath et al., 2004). The majority of participants were aged between twenty-six and forty-five (45.4%). Twenty-five individuals (22.7%) were aged between twenty-six and thirty-five and twenty-five individuals (22.7%) were aged between thirty-six and forty-five. Conversely, only seven individuals (6.4%) were aged over sixty-five and only fourteen (12.75) aged under twenty-five. The ethnic background of individuals included 42 (38%) participants who described their ethnicity as "White" and thirty-six (32.7%) Black African and Black Caribbean participants. Participants also included four individuals (3.6%) of Bangladeshi ethnicity and two (1.8%) each of Indian, Pakistani and Chinese ethnicity. Twenty participants (20.1%) marked their ethnicity as "other" which included two Afghans (1.8%), two Sri Lankans (1.8%), two Turks (1.8%), two individuals who described their ethnicity as mixed (1.8%) and one participant (0.9%) each of Arab, Greek, Libyan and Mauritian ethnicity.

The employment status of participants was diverse, with 47 individuals (42.7%) not in paid employment, and only nine individuals (8.2%) employed full time.

Educational status was also varied with thirty-three individuals classing themselves as having no qualifications (30%) and only one individual (0.9%) classing themselves as postgraduate.

The descriptive characteristics for the predictor and outcome variables were assessed. Reports of social support were high with a mean score of 3.45 ($SD = 1.16$), in a scale ranging between 1-5. The mean score for side effects was high ($M=42.36$, $SD=11.80$) at baseline and remain high at 6-month follow-up. The mean score for drug use was low ($M=2.16$, $SD=1.38$) at baseline and increased slightly at 6-month follow-up ($M=2.97.14$, $SD= 1.73$). According to the DAST 10 scoring instructions scores of 1-2 are considered “low” with scores of 3-5 considered “intermediate”.

A brief illustration of some of the demographic characteristics of the study’s participants is provided in table 1. While the descriptive statistics for the factors assessed are outlined in table 2.

Table 1. Summary of demographic data

| | Frequencies | Percentage |
|------------------------|--------------------|-------------------|
| Age | | |
| 18-25 | 14 | 12.7 |
| 26-35 | 25 | 22.7 |
| 36-45 | 25 | 22.7 |
| 46-55 | 20 | 18.2 |
| 56-65 | 19 | 17.3 |
| over 65 | 7 | 6.4 |
| Gender | | |
| Male | 73 | 66.4 |
| Female | 37 | 33.6 |
| Employment | | |
| FT | 9 | 8.2 |
| PT | 14 | 12.7 |
| Self-employed | 6 | 5.5 |
| Not in paid employment | 47 | 42.7 |
| Student | 8 | 7.3 |
| Student and working | 2 | 1.8 |
| Retired | 9 | 8.2 |
| Other | 13 | 11.8 |
| Ethnicity | | |
| White | 42 | 38.2 |

| | | |
|-----------------|----|------|
| Black Caribbean | 21 | 19.1 |
| Black African | 15 | 13.6 |
| Indian | 2 | 1.8 |
| Pakistani | 2 | 1.8 |
| Bangladeshi | 4 | 3.6 |
| Chinese | 2 | 1.8 |
| Other | 22 | 20.1 |

Marital status

| | | |
|-------------------|----|------|
| Single | 71 | 64.5 |
| In a relationship | 21 | 19.1 |
| Married | 17 | 15.5 |
| Other | 1 | 0.9 |

Education

| | | |
|------------------|----|------|
| No qualification | 33 | 30.0 |
| Vocational | 18 | 16.4 |
| GCSE's | 22 | 20.0 |
| A-Level | 20 | 18.2 |
| Undergrad | 8 | 7.3 |
| Post grad | 1 | 0.9 |

Table 2. Summary of descriptive statistics

| | Mean | Std. Deviation | N |
|------------------------------|-------|----------------|-----|
| Social Support T1 | 3.45 | 1.16 | 110 |
| Social Support T2 | 3.51 | 1.02 | 85 |
| Side EffectsT1 | 42.36 | 11.81 | 109 |
| Side EffectsT2 | 44.20 | 10.90 | 85 |
| Drug use T1 | 2.16 | 1.38 | 110 |
| Drug UseT2 | 2.97 | 1.73 | 110 |
| Consequences T1 | 5.94 | 3.05 | 109 |
| Timeline T1 | 6.84 | 3.04 | 109 |
| Personal Control T1 | 5.06 | 2.80 | 108 |
| Treatment Control T1 | 5.72 | 2.82 | 109 |
| Identity T1 | 5.88 | 2.69 | 108 |
| Concern T1 | 6.61 | 2.92 | 109 |
| Understanding T1 | 6.00 | 2.73 | 109 |
| Emotional Representations T1 | 6.26 | 2.99 | 109 |
| Consequences T2 | 5.96 | 2.35 | 85 |
| Timeline T2 | 6.46 | 2.59 | 85 |
| Personal Control T2 | 6.06 | 1.99 | 85 |
| Treatment Control T2 | 6.19 | 2.20 | 85 |
| Identity T2 | 6.32 | 2.04 | 85 |
| Concern T2 | 6.40 | 2.19 | 85 |
| Understanding T2 | 6.73 | 2.00 | 85 |
| Emotional Representations T2 | 6.69 | 1.98 | 85 |
| Adherence T1 | 2.00 | .85 | 110 |
| Adherence T2 | 2.24 | .83 | 85 |

Descriptive statistics of dropout participants.

Further analysis was conducted to compare the descriptive statistics of individuals who completed both stages of data collection (n=85) with those who did not complete the second stage (n= 25). Eighty-five individuals (77.28%) completed both stages, whereas 25 individuals (22.72%) dropped out after the first stage. The age of individuals taking part was evenly spread through different age groups.

56 males (65.88%) and 29 females (34.12%) completed both stages whereas 17 males (68%) and 8 (32%) females dropped out from the second stage. This indicates that the dropout rate was largely consistent between genders.

Analysis revealed that of the group that completed both stages, only 6 individuals (7%) described their employment as “other”. However, 7 individuals (28%) who went on to drop out from the second stage described their employment status as “other”.

35 Individuals (41%) who took part in both stages described their ethnic origin as white, while only 7 individuals (28%) who dropped out described their ethnic origin as white, suggesting that participants who described their ethnicity as white were less likely to drop out from the second stage of data collection. No other major trends were identified in the ethnic origin of individuals who dropped out of the second stage of data collection.

21 Individuals (84%) who described their relationship status as “single” dropped out from the study whereas no individuals whose relationship status was reported as

“married” dropped out. Conversely 34 (40%) individuals who described themselves as either married or in a relationship completed both stages.

Furthermore, of the individuals who completed both stages of data collection, 20 (23%) had reported their educational status as “A-Levels” whereas no one of the “A-Level” educational status dropped out from the study.

Two-time point comparisons between potential determinants and outcome variable.

A paired sample T-Test was conducted in order to evaluate changes in participant’s scores over the six-month period. Baseline and six-month follow up scores for all independent and dependent variables were compared to assess if there had been any significant changes over time. The results of paired samples T-tests revealed no significant change of scores for the dependent variable (Adherence) at baseline and six-month follow up. There were also no significant changes in scores for the independent variables with the exception of drug use, which displayed a significant increase over time ($M=-.81$, $SE=1.63$, $t=-5.21$, $df=109$, $p<0.001$). The descriptive statistics for changes to each independent and dependent variable over time can be found in table 3.

Table 3. Summary of changes in baseline and six-month follow-up scores for all variables.

| | Mean Differ- ence | Std. Devi- ation | Std. Error Mean | t | Df | Sig. |
|--------------------------------|-------------------------|---------------------|--------------------|-------|-----|--------|
| Adherence | -.11 | .82 | .09 | -1.19 | 84 | .235 |
| Drug Use | -.81 | 1.63 | .16 | -5.21 | 109 | <0.001 |
| Social Support | .09 | .89 | .09 | 1.06 | 84 | .313 |
| Side Effects | -1.65 | 10.54 | 1.14 | -1.44 | 84 | .153 |
| Consequences | -.14 | 2.14 | .23 | -.61 | 84 | .544 |
| Timeline | .42 | 2.11 | .23 | 1.85 | 84 | .067 |
| Personal Control | -.89 | 2.27 | .25 | -3.64 | 84 | <0.001 |
| Treatment Control | -.24 | 1.78 | .19 | -1.22 | 84 | .227 |
| Identity | -.18 | 1.90 | .21 | -.86 | 83 | .394 |
| Concern | .27 | 2.15 | .23 | 1.16 | 84 | .248 |
| Understanding | -.48 | 2.21 | .24 | -2.02 | 84 | .047 |
| Emotional Represen- tations | -.39 | 2.27 | .25 | -1.57 | 84 | .119 |

9.2 Research Question 1:

Are demographic characteristics, perceived levels of social support, illness perceptions, drug use and side effects at baseline associated with adherence both at baseline and six-month follow-up.

One-way between-groups analyses of variance were conducted for the effects on adherence at baseline and six-month follow-up time points by demographic independent variables (to explore the impact of employment, ethnicity, marital status, age, gender and education on adherence).

As depicted in table 4 there was no statistically significant difference in adherence at baseline between groupings on the six demographic factors.

Table 4. Associations between demographic factors at baseline and adherence at baseline.

| | F | df1 | 2f2 | Sig. |
|-------------------|-------|-----|-----|-------|
| Age | .115 | 2 | 107 | .891 |
| Gender | .291 | 2 | 107 | .748 |
| Employment | .650 | 2 | 105 | .524 |
| Ethnic Background | .695 | 2 | 107 | .501 |
| Education | 5.492 | 2 | 99 | .005 |
| Marital status | 0.120 | 2 | 107 | 0.887 |

There was no statistically significant differences between levels of adherence at baseline, based on age ($F(2,107)=.115$, $p=.891$), employment ($F(2,105)=.65$, $p=.524$), ethnic background ($F(2,107)=.695$, $p=.501$), marital status ($F(2,107)=.120$, $p=.887$) and gender ($F(2,107)=.291$, $p=.748$) at baseline. There was also no statistically significant difference between adherence at baseline and education at baseline, ($F(2,99) = 5.492$, $p=.005$).

Similarly, the same process was repeated for the six-month follow up stage, as depicted in table 5. Results at T2 showed no statistically significant differences between demographic groups: age ($F(2,82)=2.14$, $p=.124$), employment ($F(2,82)=1.67$, $p=.194$), ethnic background ($F(2,82)=1.01$, $p=.369$), marital status ($F(2,82)=.293$, $p=.747$) and gender ($F(2,82)=3.74$, $p=.028$) on adherence at six-month follow-up. There was also no statistically significant difference on levels of adherence at six-month follow-up and education at six-month follow-up, ($F(2,78) = 3.82$, $p=.026$).

Table 5. Associations between demographic factors at six-month follow-up and adherence at six-month follow-up.

| | F | Df | Df2 | Sig. |
|-------------------|------|----|-----|------|
| Age | 2.14 | 2 | 82 | .124 |
| Gender | 3.74 | 2 | 82 | .28 |
| Employment | 1.67 | 2 | 82 | .194 |
| Ethnic Background | 1.01 | 2 | 82 | .369 |
| Education | 3.82 | 2 | 82 | .026 |

Pearson's' correlations were conducted between predictor variables (social support, illness perceptions, drug use and side effects) at baseline and six-month follow-up and adherence at baseline and six-month follow-up.

As illustrated in Table 6, correlation analysis revealed that social support displayed a longitudinal relationship with adherence as it was associated with adherence at baseline ($r=.418$, $p<.01$). While social support at six-month follow-up was associated with adherence at six-month follow-up ($r=.574$, $p<.01$).

Baseline adherence were associated with both baseline personal control ($r=.272$, $p<.01$) and treatment control ($r=.456$, $p<.01$) as well as six-month follow-up personal control ($r=.304$, $p<.01$) and treatment control ($r=.319$, $p<.01$). Furthermore, adherence at six-month follow-up was associated with six-month follow-up scores for understanding ($r=.284$, $p<.01$).

Thus, in relation to research question 1, the results suggest that social support, personal control and treatment control were significantly associated with adherence both at baseline and at six-month follow-up, while understanding and emotional representations are significantly associated with adherence but only at six-month follow-up.

Table 6. Correlations between potential predictor factors and adherence at baseline and six-month follow-up.

| | Adherence T1 | Adherence T2 |
|-------------------|---------------|---------------|
| Social Support | | |
| T1 | .418** | .246* |
| T2 | .292** | .574** |
| Side Effects | | |
| T1 | -.046 | -.114 |
| T2 | -.069 | .091 |
| Drug Use | | |
| T1 | .061 | -.049 |
| T2 | -.180 | -.043 |
| Consequences | | |
| T1 | .061 | -.017 |
| T2 | .083 | .201 |
| Timeline | | |
| T1 | .090 | .045 |
| T2 | .051 | .205 |
| Personal Control | | |
| T1 | .272** | .155 |
| T2 | .304** | .361** |
| Treatment Control | | |
| T1 | .456** | .277* |
| T2 | .319** | .362** |
| Identity | | |
| T1 | -.008 | -.097 |
| T2 | -.025 | .139 |
| Concern | | |

| | | |
|---------------------------|-------|---------------|
| T1 | .060 | .066 |
| T2 | .031 | .250* |
| Understanding | | |
| T1 | .232* | .088 |
| T2 | .175 | .284** |
| Emotional representations | | |
| T1 | .007 | -.051 |
| T2 | .062 | .284** |

Note: * $p < .05$, ** $p < .01$

9.3 Research question 2:

Which of the baseline factors examined (demographic characteristics, perceived levels of social support, illness perceptions, drug use and side effects) are the strongest predictor of adherence, both at baseline and six-month follow-up?

The baseline variables that were significantly correlated with adherence at baseline and six-month follow-up were entered in a multiple linear regression model. Given multiple correlations were undertaken and to avoid type 2 error, only findings significant at $p < 0.01$ were added in the regression model. As this study was exploratory a standard multiple regression analysis was utilised with independent (predictor) variables entered simultaneously as no previous research or theoretical model could guide the choice of variables in each step. The predictors included in the regression were based on significance. There were no demographic characteristics controlled for in the regression model, since there was none significantly ($p < 0.01$) associated with adherence. At baseline, Social Support, Treatment Control, and Personal Control were all significantly associated with adherence at $p < 0.01$ level and thus all included in the regression. As shown in Table 7, this model suggests that at baseline, the independent variables explained 29.8% of the variance in adherence. Furthermore, baseline Treatment Control was the strongest determinant of baseline adherence ($\beta = .407$ [.405-.095], $p = .000$) followed by Social Support ($\beta = .282$ [.682-.214], $p = .002$). Conversely Personal Control ($\beta = -.012$ [-.012-.095], $p = .901$) was not a significant determinant as illustrated in Table 7.

Table 7. Regression model of Baseline Independent Variables with Baseline Adherence as dependent variable.

| | b | SE b | β |
|--------------------|-------|--------------------|---------------|
| (Constant) | 11.17 | .761 | |
| Social Support | .682 | .214 | .282* |
| Personal Control | -.012 | .095 | -.012 |
| Treatment control | .405 | .095 | .407** |
| R-squared | .317 | Prob (F-statistic) | <0.001 |
| Adjusted R-squared | .298 | | |
| SE of regression | 2.35 | | |

Note: * $p < .05$, ** $p < .01$

There were no baseline predictor variables that were significantly ($p < 0.01$) associated with adherence at six-month follow-up. Therefore, no further regression model was explored.

Thus, in relation to Research question 2, the results suggest that baseline independent variables potentially determined 29.8% of the variance in baseline adherence with treatment control and social support the strongest potential determinants.

SECTION 3.

DISCUSSION

This study looked at the associations between adherence to anti-psychotic medication and purported predictive factors; social support, illness perceptions, illicit substance use and side effects. Demographic factors and characteristics were also reviewed. The results suggested that social support, treatment control and personal control were significantly associated with adherence and that treatment control and social support were potential determinants of adherence. Each of these factors encompasses a broad range of features. Given the unique nature of anti-psychotic medication and the vagaries of psychosis, these findings should be interpreted in light of a number of confounding factors. In order to fully address these stipulations, it is imperative to discuss the societal and methodological caveats involved.

The results of this study found that social support was significantly associated with adherence both at baseline and at follow-up and that social support at baseline was a potential determinant of adherence to anti-psychotic medication. This adds to the accumulative body of Health Psychology research, which suggests that social support improves outcomes across a range of health conditions (Jolley et al., 2014). However, research has suggested that the concept of social support is ill-defined and requires careful specification (Brugha 1995). Regrettably, many individuals with

psychosis often suffer from social dysfunction and their social relationships and networks are reportedly reduced (Macdonald, Hayes, Baglioni Jr, 2000). Nevertheless, although the size of the network is reduced, that may not necessarily reflect upon the level of support. In research, social support is largely represented by the size of the network with some evidence suggesting that reduced networks equate with a deficiency of close relationships (Norman, Malla, Manchanda, Harricharan, Takhar & Northcott, 2005). The terms social support and social networks are subjective and multidimensional and thus difficult to quantify and measure. Research into the phenomenon has utilised a variety of measures in an attempt to explore these concepts in mental health populations and investigating these methods to ensure they are robust may offer additional insight.

As this study utilised a quantitative approach the Duke-UNC Functional Social Support Questionnaire (Broadhead et al., 1988) was used. This is an eight-item measure involving the perceived functional elements of social supports (Broadhead et al., 1988). It has been widely used in various settings and numerous studies have highlighted its average test–retest reliability, construct and concurrent validity and internal consistency (Broadhead et al., 1988; Isaacs, 2011; Mas-Expósito et al., 2013). The measure incorporates a five-item ‘Confidant’ support scale which comprises the practical aspects of social support including the opportunity to talk to someone regarding employment, financial or domestic concerns, to be provided with advice and social invitations and a three-item ‘Affective’ support measure pertaining to love and affection, individuals who care when ill (Castle, Slade, Barranco-Wadlow & Rogers, 2008). The overall total combines both of these sub-scores. Historically, a wide variety of measures have been utilised to measure social support, ranging from simply

counting the number of friends to more refined comprehensive measures. This reflects the wide range of concepts that are put forward to encapsulate a definition of social support. An in-depth review by Gayer-Anderson & Morgan in 2013 investigated all studies exploring social support and support networks amongst individuals with first episode psychosis, psychotic experiences or schizotypal traits. The authors reported that previous research had largely concentrated on any one of three categories of support. This included the “perception of support”, relating to whether the individual believed that they had others to help them and were valued in relationships, “provisional support” including emotional, financial and practical assistance and the “structure of support networks” outlining the number and frequency of contacts. Overall it was presumed that the more contacts the greater the level of support (Gayer-Anderson & Morgan, 2013). However, some people may feel more comfortable with having a small number of social contacts and may view robust support provided by one person as adequate. The individuals own satisfaction with the support provided may be more relevant.

Social support is reportedly reduced amongst people with psychosis, with the majority of support derived from caregivers and family members, thus placing particular research interest in these relationships (Jolley et al., 2014). Findings from this study suggest that enhanced social support has the potential to act as a determinant of adherence to anti-psychotic medication. However, the exact way in which social support affects health and the dynamics that arbitrate this relationship are not fully clear (Gayer-Anderson & Morgan, 2013). Health outcomes may be affected by elevated social support acting as a shield against stress; it can influence affective states, or help alter behaviour. This could occur directly through hormonal and neuroendocrine

impact on the immune system, or indirectly by influencing lifestyle, health behaviours or other features of social and psychological functioning (DiMatteo, 2004). However, previous studies have primarily focused on the impact of social support amongst the general population or those diagnosed with a physical health condition. The unique nature of psychosis requires focus on the specific ways that social support mediates the link to adherence to treatment for people with mental illness. This paper will attempt to discuss some of the factors that may have influenced its findings.

This study utilised the FSSQ, a sophisticated measure which has been validated to measure social support in a wide range of settings. However, social support is a capacious multidimensional concept which may differ for different individuals. Other ways of measuring social support include looking at distinct dimensions of social support and research utilising this approach have found similar results to the present study (DiMatteo, 2004). Empirical work has tended to confirm the existence of distinct dimensions of social support, for individuals suffering from psychosis. Newcomb & Chon (1989) employed data gathered from 793 individuals and derived three main forms of support. The first refers to support type, denoting the amount of support received and satisfaction with it. Self-completion questionnaires may generally be appropriate in measuring this dimension. However, in a therapeutic situation more detail would be required in order to identify sources of dissatisfaction (Brugha, 1995). The second form was accounted for by sources of support, such as family, friends and organisations. Social support network measures would appear suitable for measuring this (Brugha 1995). The third form was that of support functions, which incorporated both affectively important functions such as psychological and emotional distress and intimate relationships (emotional support), and more contributory

functions such as finances, health, work (tangible support). Thus, a measure of supportive networks may be insufficient for this population as the quality of tangible and emotional support should also be explored. An alternative measure would be to use an interview based approach which would have allowed participants to discuss concepts and sources of support in greater detail.

Future research such focus on various forms of social support and its impact upon mental health. Practical issues such as financial support can often be overlooked although this may have a substantial impact and is an important form of support. Recent times have seen substantial changes in the standards and delivery of psychiatric care. In line with the introduction of anti-psychotic medication there has also been increasing awareness of the importance and impact of adequate social support. The association between social support and health outcomes has received a substantial amount of devotion in health psychology and behavioural medicine research. Social support is reported to guide and enhance the capacity to adjust to and live with illness and it is believed that the relationship between social support and health may be facilitated by adherence (Dunbar-Jacob & Schlenk, 2001). Backing and assistance from a support network of friends and family has been associated with enhancing patient adherence by heightening optimism and self-esteem, cushioning the stresses of being ill, reducing depression, improving health related behaviour and providing practical assistance (DiMatteo, 2004).

Our findings reveal that Social Support impacts upon adherence to anti-psychotic medication. Social Support is acknowledged to impact upon mental health and has

a role in both mental illness prevention and recovery. Research has stressed that it is a key influence upon the perceived severity of symptoms, adaptations and health outcomes amongst patients diagnosed with schizophrenia (Hamideh, Al-Magaireh, Abu-Farsakh & Al-Omari, 2014). It is considered a determinant in advancing recovery, can positively affect both physical and mental health and perhaps most significantly, high levels of social support is purported to act as a defensive shield that can positively enhance the quality of life of people with psychosis while decreasing the severity of their symptoms (Mas-Exposito, Amador-Campos, Gomez-Benito & Lalicat-Jo, 2012).

Our results also revealed that treatment control as conceptualised by Leventhal's Self-Regulation Model was the strongest determinant of adherence to anti-psychotic medication as compared to the other variables considered. Poor insight into one's treatment can, therefore, be considered a primary risk factor as adherence is essential in both recovery and relapse prevention for individuals with psychosis. These findings have important implications for interventions and further research into adherence. It suggests that Leventhal's Self-Regulation Model provides an innovative way to comprehend perceptions and responses in individuals with psychosis.

CHAPTER 10. Insight and treatment control.

The results of this study highlight that the controllability that individuals perceive to have on their treatment will affect their adherence to treatment and this impact remains extant over time. Within mental health settings the term “lacking in insight” is often erroneously used to outline a commonly held view that individuals who do not accept their illness will not adhere to their treatment (Coffey, 1999). Our findings therefore have significant clinical implications. People’s perceptions of their illness, influence their adherence to medication. According to the Self-Regulation Model, treatment control denotes perceptions of controllability/curability, which refers to the extent to which individuals believe they will be able to recover from or control the illness through treatment (Leventhal et al., 1998, 2001).

Individuals diagnosed with mental illness often have little or no insight into their condition. They often do not consent to treatment. This results in a lack of engagement and trust towards health care professionals (Andreasen & Black, 2014). Thus, developing an effective therapeutic relationship is vital. Research suggests that the term “lacking in insight” can be incorrectly used in clinical settings to refer to the belief that patients who do not accept their diagnosis and will not adhere to treatment (Coffey, 1999). Use of the term ‘insight’ into one’s illness’ can also be contentious within mental health settings, as classifying a psychological problem as an illness can in itself be seen as a form of coping. The nature of mental health conditions can influence the ability to reflect upon one’s own experiences and thus to construct an illness perception (Fortune et al., 2004).

With psychological conditions, the distinction between being considered ill or healthy is at least partially a subjective consideration (Witteman, Bolks & Hutschemaekers, 2011). Individuals diagnosed with a mental health condition often do not believe themselves to be ill, even if they recognise that they have an affliction.

The potential relevance of the Self-Regulation Model's representations of illness insight can help explore how people experience their mental health problems in relation to treatment outcome is recognised. Illness perceptions have been studied in a few disorder-specific client groups, including schizophrenia (Lobban et al., 2004, 2005), depression (Fortune et al., 2004; Manber et al., 2003) and eating disorders (Stockford et al., 2007). A recent study (Witteman, Bolks & Hutschemaekers, 2011), investigated the appropriateness of using the IPQ in the mental health domain and suggested that the self-regulation model does seem applicable to clients with mental health conditions.

Research suggests that poor insight is a common characteristic in psychosis, particularly amongst individuals suffering from schizophrenia with prevalence rates of poor insight reportedly as high as 98% (Novick et al., 2015). A crucial element to consider when deliberating on the nature of treatment control in psychosis, is the nature of recovery from a psychotic episode. Individuals experiencing severe psychotic symptoms are very rarely aware of this and they may therefore not be fully aware of how their symptoms manifest. Because of the time it takes for anti-psychotic medication to take effect, people may not be able to distinguish symptoms with side effects from anti-psychotic medication or associated treatment with improvements in their mental health (Kemp & David 1996). Furthermore, according to research illness perceptions

effected the duration of untreated psychosis which in turn has an impact on severity of symptoms (Drake et al., 2000). Suggesting that these issues may be multifactorial and interrelated. This is backed by the findings from this study which highlighted that scores on the BIPQ were also associated with social support, side effects and drug use.

CHAPTER 11. Use of the Self-Regulation Model and measures of illness perceptions.

Our results support the suitability of using the Self-Regulation Model due to its multidimensional approach in making sense of illness and this has wide implications for use within mental health settings. Psychosis has biopsychosocial causes and is contextualized within a cultural setting. To fully comprehend the impact of causal attributions, the influence of psychosocial factors and cultural views toward psychotic conditions should be considered in addition to investigating the effects of biological causes on perception of controllability (Mak et al., 2014). Furthermore, it is beneficial to consider the broader perception of psychosis, in addition to the attributions of controllability and stability. Therefore, the Self-Regulation Model can be used in an attempt to understand how the public's multidimensional illness perceptions of psychosis are associated with their adherence to anti-psychotic medication.

To date the Self-Regulation Model has been productively utilised in attempts to further understandings of health outcomes in various conditions including chronic fatigue syndrome, chronic pain, cardiovascular disease, fibromyalgia, cancer, traumatic brain injury and numerous other conditions (Wearden & Peters, 2008; Snell et al., 2013; Sivell et al., 2011). There has been increasing exploration of illness perceptions in mental health utilising the Self-Regulation model. A comprehensive 2013 review by Baines & Wittkowski examined 13 studies utilising the Self-Regulation model in mental health and concluded that while mental illnesses were often viewed as cyclical and chronic, use of the Self-Regulation model was largely supported. The

most common instrument utilised to provide a quantitative assessment of the relationship between the five components of illness representation; identity, timeline, consequences, cause and control/cure as described in Leventhal's Self-Regulatory Model (Leventhal et al., 1984, 1997) is the Illness Perception Questionnaire (IPQ; Weinman et al., 1996). It has been used in studies of illness perceptions in patients with a wide range of conditions. Subsequently, a revised version of the IPQ measure referred to as the IPQ-R (Moss-Morris et al., 2002), expanded upon the original scale utilising additional items, subscales and incorporating an assessment of patients' perceptions on how well they comprehend their illness and their emotional response to the illness.

The length of both scales resulted in a need for a shorter version which was addressed with the publication of The Brief Illness Perception Questionnaire (Brief IPQ; Broadbent et al., 2006). During the patient involvement group that took place prior to data collection, participants commented on the ease of filling in the measure, with all items offered in the form of a ten-point Likert scale. The BIPQ measured various aspects of illness perception; cognitive representations (which involve the extent of individual control over the disorder, views on the gravity, length and impact of the condition and effectiveness of a cure), comprehensibility (of the condition) and emotional representations (negative feelings regarding the condition). Previous studies have highlighted its reliability and validity and it had been appositely applied in studies involving individuals with psychosis (Broadbent et al., 2008).

The use of the BIPQ allowed us to investigate how illness perceptions evolved over time, considering the purported cyclical nature of human self-regulation. Our findings support the view that interventions to enhance adherence to anti-psychotic medication would benefit from a focus on treatment related attitudes. The results provide sustenance to contemporary research which has advocated therapeutic techniques for interventions based upon Leventhal's Self-Regulation Model (Wearden & Peters, 2008).

CHAPTER 12. Importance of therapeutic relationships upon treatment control in psychosis.

The crucial importance for mental health practitioners to develop therapeutic relationships may have impacted the concepts of treatment control experienced by their patients. The findings from this study and others indicate that the relationship between side effects, illness perceptions and adherence is complex and multifaceted. Illness perceptions relating to treatment control can be used to elucidate how individuals construct a personal representation of their disorder so that they can better understand and counteract their circumstances (Gómez-de-Regil et al., 2014).

The present study expanded upon previous research into illness perceptions, highlighting the relationship between treatment control and adherence to anti-psychotic medication. The findings from this study can help inform the focus of future interventions. Future research may focus on enhancing treatment control and whether improvements result in enhanced adherence to treatment. The long-term impact of treatment control emphasised by the results of this study suggests that including patients in treatment choices, in addition to understanding and accounting for their beliefs about treatment within clinical mental health settings, is vital to their adherence to treatment.

The unique nature of mental illness may also help explain the heightened impact of treatment control as a potential determinant of adherence and why personal control

was univariately significant but did not prove to be a multivariate determinant of adherence. The engagement levels of patients within mental health services plays a key role in treatment and is considered dependent upon the development of a therapeutic relationship based on trust, empathy and mutual understanding. Individuals diagnosed with mental illness often have little or no insight into their condition. They often do not consent to treatment. This can result in a lack of engagement and trust towards health care professionals (Andreasen & Black, 2014). Thus, treatment control may have a crucial impact. The necessity for mental health practitioners to develop an effective therapeutic relationship may impact the concept of treatment control experienced by their patients. Developing an effective therapeutic relationship is vital. The engagement levels of patients with mental health services plays a key role in treatment and is considered dependent upon the development of a therapeutic relationship based on trust, empathy and mutual understanding. Research into the impact of illness insight upon therapeutic relationships has enhanced awareness of its influence. However, relatively little research has focused on the impact of therapeutic relationships upon treatment control amongst individuals diagnosed with psychosis. It can be argued that one of the main findings of this research is that it is not necessarily the amount of insight into treatment that a patient has which has the biggest impact on adherence but rather the amount of perceived “control” over their treatment.

Hitherto, relatively little research has explored strategies to increase insight in patients suffering from psychosis (Novick et al., 2015). The Self-Regulation Model may provide a useful framework for understanding how a patient’s representation of their illness influences their adherence to anti-psychotic medication as specified by the

results of this study. This could potentially have a profound impact upon treatment regimens within mental health, as illness insight has been shown to have a significant impact on therapeutic relationship for inpatients suffering from schizophrenia and schizoaffective disorder and an effective therapeutic relationship is often considered a cornerstone to effective treatment (Lehrer & Lorenz, 2014).

CHAPTER 13. Demographic Findings

The results of this study indicated that demographic characteristics did not have a significant impact upon adherence. However, the demographic characteristics of the present study show interesting trends. Only 15.5% of those taking part were married. Other findings revealed that at the first stage of data collection only 33% of participants were female. This contrasts with previously reported rates indicating that males are only moderately more likely to be diagnosed with the condition (McGrath et al, 2004). This study also found that participant's gender revealed significant correlations with employment status, ethnic background, marital status, drug use, social support and illness perception. These findings are revealing and there are a number of possible explanations. Overall, it is reported that mental health issues affect males and females equally, with no consistent gender differences in prevalence rates reported. However, certain mental health issues are more common in females than males and vice versa. When investigating the role of gender in mental health it is important to be aware of the division between the relatively low-prevalence of severe mental health disorders such as schizophrenia and bipolar disorder, where prevalence rates have no significant gender differences have been consistently conveyed, and the high-prevalence disorders of anxiety and depression where large gender differences in rates have been consistently reported. Depression accounts for 41.9% of overall psychiatric disorders in females, and just 29.3% in males (Murray & Lopez 1996).

Numerous investigations have recognised clear gender differences in social support which appear constant across the life cycle, with females consistently reporting to

receive more support than males (Matud, Ibañez, Bethencourt, Marrero, & Carbal-leira, 2003; Laireiter & Baumann, 1992; McFarlane et al., 1981). Findings indicate that although males often tend to socialise in groups, from childhood females report a larger number of more intimate personal friendships and relationships and larger supportive networks than males (Laireiter & Baumann, 1992; McFarlane, Neale, Norman, Roy, & Streiner, 1981). Research has suggested that females are more inclined to seek out a support network to provide sustenance during traumatic events and times of stress, whereas males attempt to try to manage on their own (Taylor, 2002). Good social support networks have been viewed as a shield against stress and a variety of illnesses. The supportive social relationships that are more prevalent in females may provide greater protection for females with psychosis than males. These differences could potentially have substantial implications upon health promotion, seeking support in times of need and subsequently adherence.

Gender disparities in mental health are an extremely significant topic which appears to endure a paucity of research. Although gender differences in rates of overall mental disorders, including disorders such as schizophrenia, are negligible, there are significant gender differences in rates for somatic complaints including depression and anxiety with females almost twice as likely to be diagnosed with anxiety disorders. (McManus, Bebbington, Jenkins & Brugha 2016). Females appear to face increased burden due to the gender discrimination which is existent in society. Studies have indicated that females are affected by additional pressures such as multiple roles, poverty, malnutrition, overwork, domestic violence and sexual abuse to a larger extent than males (Martin-Merino, Ruigomez, Wallander, Johansson & GarciaRodriguez, 2009). Traumatic life events are a predictor of depression (Bromley et

al. (2014). A greater understanding of gender inequalities is essential in order to promote the formulation and implementation of health policies that address female's needs and concerns should be recognised in order to develop a gender sensitive framework that can be adopted to improve adherence to anti-psychotic medication in mental health care practice and research.

Furthermore, less than 14% of participants described themselves as full-time or self-employed, with employment status showing significant correlations with both age and gender. The results also highlighted the fact that participants who self-reported higher educational status were less likely to drop out from the second stage of data collection. 61.8% of participants in this study belonged to ethnic minority subgroups. Members of ethnic minority groups were also more likely to drop out from the second stage of data collection. However, there was no significant association between ethnicity and adherence.

The overrepresentation of ethnic minorities in mental health statistics has been the subject of significant debate and research (Tsang, Fung & Corrigan, 2008). There is a theoretical underpinning as to why there may be ethnic differences in adherence to medication regimes. Differences in communication styles may result in increased difficulties in conveying symptoms, side effects and concerns. Certain cultures may also display increased lack of acceptance of psychosis and anti-psychotic medication may be seen as irrelevant to the problem (Tsang, Fung & Corrigan, 2008). In order to improve the cultural sensitivity of mental health services, matching patients with professionals of the same ethnic origin is commonly endorsed, with patients

reportedly preferring treatment from professionals who shared their ethnic background (Pinikahana, 2005).

The National Institute for Health and Clinical Excellence guidelines on adult mental health (NICE clinical guidance 136) recommends that healthcare professionals working with people with psychosis should confirm competency in working with people from diverse ethnic and cultural backgrounds in order to explain the psychosis and treatment options, while addressing cultural and ethnic differences in treatment expectations and adherence, for people from diverse ethnic and cultural backgrounds (NICE 2002). Studies have reported that ethnic minority patients suffering from psychosis are more likely to remain in treatment when working with a counsellor of the same ethnic background or language group (Ziguras et al., 2001). Removing cultural barriers and communication issues may impact upon adherence and thus have a significant impact upon outcomes.

Previous research has proposed that socio-demographic factors correlate with adherence to anti-psychotic medication (Pinikahana, 2005). However, the results of correlations carried out by these studies have been inconclusive (Tsang, Fung & Corrigan, 2008). Further research in this area is required and mental health practitioners should work to ensure that culturally appropriate treatment is delivered to people from various ethnic and cultural backgrounds.

CHAPTER 14. Patient perspectives in identifying side effects and the impact of professionals.

Our findings did not reveal the severity of side effects to be a significant determinant of adherence to anti-psychotic medication. A number of factors may have mediated these findings. Professional literature suggests that atypical anti-psychotics will be more appealing to patients because of the lower risk of side effects. However, there appears to be very little clear research evidence to support this commonly held view of many mental healthcare professionals (Coffey, 1999). Crucially, relatively little research has focused on the patient's own experience of their side effects. The majority of previous studies focused on professional views rather than the view of patients. This is a common issue in mental health settings where patients may often be perceived as lacking insight into their condition and do not always consent to treatment. Despite reductions in the severity of side effects since the introduction of newer atypical anti-psychotic medications, there has been no significant change in the rates of adherence compared to traditional typical anti-psychotics (Acosta et al., 2009). Clinician's views regarding side effects suggest that they feel extrapyramidal effects are the most troubling for patients but there is little evidence to suggest that patient themselves share this view (Coffey, 1999). The fact that this study attempted to address patient rather than professional views of side effects may offer an explanation as to why findings from this study differ from previous associations between side effects and adherence.

Other mediating factors which may have impacted upon results include the individual experience of the patient, professional input and the way that this can go on to impact upon illness perceptions. It can be very difficult for some patients to determine side effects from the symptoms of psychosis particularly during the early stages of treatment (McCann et al., 2009). All of these factors can further complicate identifying side effects for patients. While anti-psychotic medication may reduce symptoms, patients may be reliant on professionals to help them identify side effects and raise illness perceptions. Conscientious and sensitive treatment by clinicians to explore the patients' experiences of side effects is essential and it is vital that these views are not dismissed as irrelevant. However, a survey of psychiatrists has suggested that the majority believed that fully informing patients of possible side effects would lead to adherence problems, while community mental health nurses were reportedly ineffective at identifying several of the traditional side effects of anti-psychotic medication and many clinicians underestimate the extent of suffering caused by side effects (Coffey, 1999).

CHAPTER 15. Measures of side effects.

The results of this paper suggest that the severity of side effects is not a significant determinant of adherence to anti-psychotic medication. Ethicists recommend that the autonomy of the patient should always be respected and this needs to be encouraged during inpatient admissions under the Mental Health Act (1983) or acute episodes when anti-psychotic medication is prescribed (Coffey, 1999). A collaborative, sensitive non-judgmental approach adopted by mental health care professionals which addresses patients' concerns regarding side effects may expand the patient's confidence in treatment. Choosing an appropriate measure of side effects that assessed patient's views and addressed the issue of sexual side effects raised in the patient involvement groups during this study was therefore considered imperative.

Previous findings have suggested that 74% of patients who discontinued long term use of anti-psychotics did so due to sexual side effects (Lambert et al., 2004). This study attempted to utilise a measure which inspected side effects to anti-psychotics and specifically addressed sexual dysfunction, as both the focus group prior to data collection and previous research (McCann et al., 2009; Lambert et al., 2004), has highlighted the distressing impact of sexual side effects upon patients.

A number of measures focus primarily on Extra Pyramidal Symptoms and were therefore not used in this study. More recent measures provide scales which can be self or physician completed and address a wide range of side effects related to both typical and atypical anti-psychotics. Of the self-completion scales The Glasgow Anti-Psychotic Side Effect Scale (GASS) is often considered the most popular in the United Kingdom and widely used in clinical settings. The GASS rates metabolic and

neuromuscular side effects as well as sexual dysfunctions (Nystazaki et al., 2014). It was therefore considered germane to all relevant issues and chosen for use in this paper. The fact that the GASS measure elucidates patients rather than professional views while addressing sexual dysfunction, addressed the concerns raised in the patient involvement groups and provides additional credence to the findings of this study.

The National Institute for Clinical Excellence guidelines on adult mental health (NICE clinical guidance 136), recommends that the selection of anti-psychotic medication should be made by the patient and healthcare professional collaboratively, incorporating the views of carers if the patient agrees. Clinicians should offer information and discuss the likely benefits and potential side effects of medication, including extrapyramidal, metabolic, cardiovascular, hormonal, sexual and social sequelae.

Research suggests that the term “lacking in insight” can be incorrectly used in clinical settings to refer to the belief that patients who do not accept their diagnosis and will not adhere to treatment (Coffey, 1999). The findings from this study and others indicate that the relationship between side effects, illness perceptions and adherence is complex and multifaceted.

CHAPTER 16. Drug Use and Adherence.

The results of this paper suggest that drug use is not a significant determinant of adherence to anti-psychotic medication. An ample body of research has suggested that illicit substance use is common amongst individuals suffering from schizophrenia (Asher & Gask, 2010; Bahorik et al., 2014; Margolese et al., 2004; Fowler et al., 1998). Increased drug use amongst patients has been linked to numerous adverse outcomes including earlier onset of the disorder, increased rates of relapse, rehospitalisation, suicide and non-adherence to medication (Asher & Gask, 2010; Akvardar et al., 2004). These previous studies have used the Drug Abuse Inventory (Skinner, 1982) to assess substance use. The present study used The Drug Abuse Screening Test (DAST-10) to assess drug use, as the DAST has been viewed as an improvement upon other widely used measures such as the DAI (Skinner, 1982) and offers moderate to high levels of test–retest, validity, sensitivity, specificity within a wide scale of populations including psychiatric inpatients and outpatients. (Yudko et al., 2007). The use of different measures may explain the discrepancies in the results of the present studies to previous studies in the area.

The results also revealed a significant change of scores for drug use at baseline and six-month follow-up, suggesting that drug use significantly increased over time ($M=2.16$, $SE=.13$, $t=-.52$, $p<.05$). These findings promote discourse of a number of factors. Drug use is illegal and many users may have a vested interest to conceal usage (Van Dorn et al., 2012). Reviews into drug use amongst patients with psychosis have suggested that measures reliant upon patient disclosure may significantly

underreport actual usage rates, particularly during periods of acute breakdown (Bahorik et al., 2013). This may explain why the results of this study indicated that scores on drug use measures increased at the second stage of data collection. As participants became more familiar with the purpose of the study and less concerned by legal ramifications, they may have been more accurate in disclosure. Recent studies have explored the accuracy of reported substance use amongst adults with schizophrenia and have incorporated tests such as urinary drug screens and hair analysis as part of a comprehensive assessment of inpatients (Van Dorn et al., 2012). Biological measures may offer increased accuracy over self-report measures in the detection of illicit substances, but they also face increased impugns regarding their use. Urine drug screening only has a small timeframe for accurate screening depending upon the substance used, with certain substances only detectable within 24 hours of use. Hair analysis offers an increased timescale to detect drug use and is reportedly less susceptible to countermeasures when compared to urine analysis (Van Dorn et al., 2012). However, both forms of laboratory testing have been accused of being over intrusive, impacting upon patient rights and have faced challenges as to whether they are statistically more accurate than self-report measures.

Research has suggested that self-report measures are actually more accurate in detecting alcohol and drug use disorders than urine and blood tests (Wolford et al., 1999). The majority of previous research utilising biological/laboratory drug testing have taken place within in-patient settings, and it may be difficult to replicate these findings in the community because of the intrusive nature of testing. Participants that were willing to take part in these tests may not necessarily be representative of the overall population of individuals suffering from psychosis. Although the majority of

previous research has focused on Europe and North America, findings from around the world have considerable variance in illicit substance use (Margoless et al., 2004), highlighting the need for representative local analyses to explore the nature and magnitude of drug use amongst local populations. Due to the legal, ethical and moral implications surrounding drug use, exploration of all mediating factors can be controversial.

SECTION 4. Clinical Implications, Future Research, Limitations and Conclusions

CHAPTER 17. Clinical Implications

Health Psychology has provided numerous theories and models to explain, describe and predict health behaviour and Health Psychologists are increasingly involved in both the design and delivery of interventions (Michie & Abraham, 2004). A strong understanding of the processes involved is required to effectively assess the therapeutic techniques utilised in interventions and how the intervention relates to theory (Michie & Abraham, 2004). This paper will attempt to identify interventions based upon the findings from this study, so that the practicality of different therapeutic techniques can be evaluated.

Although Health Psychologists are involved in the design and delivery of interventions (Michie et al., 2005), relatively few Health Psychologists work directly with patients within mental health settings and it is not standard practice for Health Psychologists to be employed within mental health wards. This may have resulted in

inadequate development of therapeutic interventions based upon the science and evidence base of Health Psychology within this setting.

The symptoms of psychosis manifest in a unique way and it is extremely rare for two individuals to suffer from identical symptoms. In order to develop, design and deliver individualised interventions, Health Psychologists would need to be experienced in working with people with psychosis, familiar with the unique nature of working within mental health settings and comfortable in providing long-term patient contact. Whereas, in order to effectively develop and properly evaluate therapeutic techniques utilised in such individualised interventions, a clear understanding of the processes involved, a comprehensive knowledge of how the intervention relates to theory and thus an experienced background in Health Psychology would appear ideal (Michie & Abraham, 2004).

The findings of this study have highlighted that treatment control, personal control and social support are all associated with adherence, while treatment control and social support were found to be determinants of adherence to anti-psychotic medication. The aim of this author is to provide an overview of illustrative examples of interventions that may be utilised based on the findings. Future research could potentially evaluate the usefulness of different therapeutic techniques which may help identify and develop more detailed interventions.

17.1 Potential use of Leventhal's Self-Regulation model in mental health Interventions.

The results of this study have indicated that personal control and treatment control are significantly associated with adherence with treatment control an effective determinant of adherence to anti-psychotic medication. This has underlined the prospect for therapeutic techniques based on Leventhal's self-regulation model within mental health settings. This offers an expedient method by which to comprehend the role of cognitive and perceptual factors in the management of mental health conditions such as psychosis and has the potential to kindle further research into the application of Leventhal's model within mental health settings. It also encourages the development of techniques to enhance treatment control and insight as a route to improve adherence to anti-psychotic medication.

The link between treatment control and adherence highlighted in this study advances a compelling argument for further research into this area. The implications of these findings could potentially serve as an important factor to be considered in clinical interventions designed to improve adherence to anti-psychotic medication. Increased awareness of how illness perceptions amongst individuals with psychosis affect emotions and treatment outcomes would enhance our understanding and aid the development of approaches to facilitate effective treatment. Therapeutic interventions which address treatment control may enhance adherence to treatment, therapeutic relationships, engagement levels, community treatment and family and

marital relationships while reducing repeated relapse, costly long-term service use and the duration of untreated psychosis (Gómez-de-Regil et al., 2014).

The core elements of the Self-Regulation Model could potentially be utilised in the formulation of patient-centred interventions for adherence for patients suffering from psychosis. Illness representations are theorised to develop from concrete experiences, and abstract information, such as awareness of the illness obtained from various sources (Leventhal et al., 1984). Interventions should emphasize the role of both cognitive and behavioural interventions to reflect the bidirectional nature of the associations between concepts as outlined by the Self-Regulation Model. Interventions to improve adherence could be conceptualised in techniques facilitating people to achieve conscious control over automatic processes (Wearden & Peters, 2008). As a parallel-processing model, the Self-Regulation Model also distinguishes the influence of cognitions on emotions and it postulates the methods to regulate emotion utilising behavioural techniques, thus the emotion regulation aspect of the model could also be utilised to develop interventions. Previous research has assessed interventions grounded in Leventhal's Self-Regulation Model and recommend that in order to maximise usefulness, future interventions should comprise components to encourage threat-focused and emotion-focused regulation procedures, the authors went on to appeal for additional research on the interaction between cognitive representations and the process by which emotion regulation strategies are selected (Cameron, Petrie, Ellis, Buick, & Weinman, 2005).

17.2 Potential interventions pertaining to treatment control.

Previous findings have reported that adherence and insight are associated with attitudes towards treatment and clinical variables (Kemp & David, 1996). The impact of developing effective therapeutic relationships and the significance of staff communication are crucial factors to be considered in mental health settings. There is increasing scope for mental health nurses in the provision of providing support and information to improve illness insight, raise illness perceptions and enhance treatment control. This would enable patients to make informed decisions and provide a way of taking an element of control over their treatment (Coffey, 1999). However, increasing information and broader educational programmes appears insufficient in improving adherence to anti-psychotic medication, as providing education and information does not equate to understanding and conceptualising the education in the manner of those providing it (Hughes, Hill, & Budd, 1997). A study exploring the impact of providing psycho-educational training to individuals with schizophrenia on medication management found it had no impact upon levels of adherence, although it did improve confidence in the consultant and medication while decreasing the fear of side effects (Hornung, Klingberg, Feldmann, Schonauer, & Schulze Monking, 1998). Thus, education may improve attitudes towards medication but not necessarily impact adherence (Coffey, 1999). It is therefore imperative that procedures are put in place to enhance one's treatment control.

Previous research utilising the Self Determination Theory as a practice model for the promotion of control, indicated that perceptions of autonomy and competence were increased by perceived autonomy support, and that alteration in autonomous motivation and in perceived competence were found to predict improvement (Williams, McGregor, Zeldman, Freedman, & Deci, 2004). This demonstrates that the principles of the Self Determination Theory provide a framework with which to explore the motivational characteristics in individuals. Adversarial approaches are unlikely to be effective in enhancing treatment control amongst individuals with psychosis, as evidence suggests that client centred approaches are more effective in the facilitation of behaviour change, with patients reportedly preferring a client centred approach in developing effective therapeutic relationships (Rubak, Sandbæk, Lauritzen, & Christensen, 2005).

The autonomy of the patient should always be respected and encouraged while exploring methods to augment treatment control. A collaborative, sensitive, non-judgemental approach is essential when dealing with behaviour change. An increasingly popular approach in working with the issue of behavioural change is Motivational Interviewing, due to its recognition of ambivalence and emphasis on working with individuals' readiness to change.

Motivational Interviewing could be adopted as a technique to develop interventions to enhance treatment control and ultimately augment adherence to anti-psychotic medication levels. This technique appears to have unique potential as mental health

patients do not always enter therapeutic sessions in a willingness to change disposition which often leads to confrontational, antagonistic and adversarial dynamics within mental health settings (Coffey, 1999). Repeatedly advising a patient regarding adherence may result in the patient taking a defensive position. Motivational Interviewing circumvents these setbacks through its “spirit” of encouraging patients to identify the positive and negative elements of a course of action, thereby fostering a collaborative therapeutic relationship.

Interventions utilising Motivational Interviewing would encourage empathetic understanding from practitioners who should be provided with training to raise awareness and understanding of the range of motivational techniques utilised within this approach. Knowledge of other behaviour change theories, such as the Stages of Change Model which supports the principles for readiness to change, and the Self Determination Theory which suggests that individuals are more likely to adopt healthy behaviours when their basic psychological needs for autonomy, competence and relatedness are supported would also be an advantage. Exploration into the utilisation of Motivational Interviewing interventions within mental health settings would appear to be an expedient area for future research.

17.3 Potential interventions to enhance social support.

The potential predictive capacity of social support upon adherence to anti-psychotic medication as highlighted in this study, can be employed in an attempt to develop interventions designed to increase adherence. In order to maximise the success of

these interventions they would need to be culturally sensitive and take into account gender differences in social support. Current National Institute for Clinical Excellence guidelines on adult mental health (NICE clinical guidance 136) recommends the use of peer support for people with psychosis to enhance service user experience and quality of life. Providing and enhancing support networks for individuals with psychosis should be viewed as a key part in community based treatment programmes. One potential way in which this could be encouraged is through the development of group exercise sessions. Exercise is often considered a neglected intervention in mental health care with scant consideration of exercise as a treatment option.

To date there has been relatively little research into the influence of group physical activity on mental health. However, some findings have suggested that group physical activity can be an effective supplementary treatment for psychosis (Faulkner & Biddle, 1999), yet the vast majority of previous research has mainly focused upon the role of exercise in assuaging the symptoms of anxiety or depression amongst non-psychiatric populations. Conversely, evidence suggests that higher rates of exercise coincide with higher rates of self-esteem, social standing and body satisfaction (Doğan et al., 2004). In light of the findings of this study, which highlighted the impact of social support on adherence to anti-psychotic medication, this has important clinical implications. The role of group exercise as a method to enhance social networks has the potential to influence outcomes and is worthy of careful deliberation, particularly when the financial connotations are considered. Hospital treatment tends to be costly and long-term in mental health disorders (Allison et al., 2009), whereas the effect of non-adherence to anti-psychotic medication is associated with detrimental treatment outcomes such as increased risk of relapse, rehospitalisation, increased

use of emergency psychiatric services, reduced psychosocial functioning, poorer prognoses, detrimental mental functioning and increased risk of suicide (Weiden et al., 2004; Beck, et al., 2011). Additionally, research suggests that a lack of knowledge of the positive aspects of exercise programmes is prevalent on many mental health wards, resulting in a lack of exercise (Acil, Dogan, & Dogan, 2008). Weight gain is a common side effect of anti-psychotic medication and in addition to the impact upon physical health can also influence self-esteem, personal relationships, destabilise wellbeing, affect morbidity and mortality and necessitate the requirement of regular medical supervision (Wolters et al., 2009).

Group physical exercise programmes are a potentially cost-effective, easily applicable and readily available addition to current mental health interventions. It could be used as an alternative to existing treatments or to supplement existing therapy aimed at raising self-esteem and overall quality of life of patients, both in a clinical environment and also for individuals residing in the community (Acil et al., 2008). Group exercise classes can be utilised as a means to develop socialisation skills and develop a supportive social network with shared goals. A recent study highlighted the associations between social support and group exercise participation (Rackow, Scholz, & Hornung, 2015). The authors found links between social support and exercising via constructs of self-regulation, such as self-efficacy. The study examined the effects of different kinds of social support (emotional and instrumental) on exercising by means of self-efficacy but also self-monitoring and action planning. The study involved participants procuring and then exercising regularly with a new exercise companion. The results indicated that emotional social support predicted self-

efficacy, self-monitoring, and action planning in participants undertaking group exercise, with emotional social support indirectly connected with exercise via the examined mediators. The effect from received emotional social support via self-efficacy contributed to the total effect. The authors suggested that actively engaging with a new exercise companion and exercising together promoted enriched emotional and instrumental social support and that support in turn promotes exercise by enabling better self-regulation (Rackow et al., 2015).

Modifying health behaviour entails maintaining the individual's motivation and interest over a protracted period of time. Health Psychology can play an important role in raising awareness for effective exercise programmes amongst mental health practitioners, encouraging in-patients to practice exercise activity, adapting programmes of peer-led group exercise for those residing in the community and developing interventions in relation to augmenting the exercise habits of patients while helping to improve self-esteem, social networks and overall well-being (Callaghan, 2004). Awareness could also be raised amongst GP's, psychiatric nurses, social workers and community CPN's to help implement exercise interventions during patient contact and possibly incorporating lifestyle assessments encouraging group exercise activity into mental health assessments.

CHAPTER 18. Future research.

Potential for future research would involve exploring the concepts of adherence to anti-psychotic medication over a longer time-scale to assess whether the trends evinced in this study persist. A theoretical possibility for future research would be to narrow the scope of the research area to focus on a particular condition or medication. Although a great deal of Health Psychology research has explored the concept of adherence, data and research into these concepts within mental health populations are rare (Dunbar-Jacob & Schlenk, 2001). The findings of this study serve as an important preliminary exploration of the association of treatment control, personal control and social support on adherence to anti-psychotic medication.

Health Psychology has provided substantial empirical evidence for the impact of the self-regulation model in exploring concepts of adherence. The findings from this study suggest that future research could focus on the concepts of treatment and personal control within mental health settings. Similarly, while Health Psychology has provided substantial empirical evidence for the association of social support with adherence in other conditions, the findings of this study emphasise the impact of social support upon adherence to anti-psychotic medication. Mental health care professionals should pay heed to the potential impact of treatment control and social support on patients. Future research should focus on the relationship between treatment control, social support and adherence. Health Psychologists should cogitate the potential of utilising interventions based around these factors to potentially augment adherence to anti-psychotic medication.

Future research should focus on the variations in social support, as it is a multi-dimensional, culturally sensitive concept. Additional investigation into these concepts and increased knowledge of how individuals with psychosis experience social support and its impact upon adherence is fundamental in developing culturally competent interventions relating to anti-psychotic medication. Although the positive impact of social support is well documented, there is a dearth of research exploring how social support varies across different cultures for individuals suffering from psychosis. The results of this study would suggest that such enquiry plays a fundamental role in the development of culturally appropriate care.

Our findings have suggested social support, personal control and treatment control to be significantly associated with adherence. In line with previous research, these relationships may be interlinked and multifactorial (Drake, Haley, Akhtar, & Lewis, 2000). National Institute for Clinical Excellence guidelines on adult mental health (NICE clinical guidance 136) recommends that mental healthcare professionals should regularly monitor for other coexisting conditions, including substance misuse. Research from this paper and others has emphasised the significance of social support on adherence to anti-psychotic medication, larger social groups amongst patients with dual diagnosis may be a mediating factor for adherence in this subgroup. Due to legal, ethical and moral implications surrounding drug use, exploration of all mediating factors can be controversial.

The onus is placed on future research to conduct thorough exploration of all mediating factors in a robust methodical manner. The associations with adherence to anti-

psychotic medication as highlighted in this study could potentially have important implications for mental health professionals. Future research should take the perceived treatment control and social support of patients into account and attempt to incorporate these concepts when designing interventions aimed at optimising adherence.

CHAPTER 19. Limitations and challenges.

Given the relatively small sample size of this study it is recognised that the sample may not necessarily be representative of the adult population prescribed anti-psychotic medication. The majority of participants were individuals residing in group living environments in the North, North East and West London areas and the sample subsequently snowballed via word of mouth. Strengths of this method of sampling include that it enabled the recruitment of participants who were self-administering their medication and not dependent on others to administer their medication, as is the case during in-patient settings. However, while the sample was made up of a range of ages, ethnic & cultural backgrounds it is conceivable that a sample comprised of individuals living in similar locations and circumstances could retain similarities in terms of economic and social backgrounds. Other noteworthy demographic findings were also observed. At the first stage of data collection only 33% of participants were female. This contrasts with previously reported rates, which indicated that males are only moderately more likely to be diagnosed with the condition (McGrath et al., 2004). This points to specific subgroups within samples which may be misrepresented in research findings. The majority of research in psychosis takes place amongst in-patient wards which are often divided into male or female only wards. However, these wards may specialise in different forms of psychotic illness. Future research should ensure that the samples included are representative of psychosis in general. A greater understanding of gender inequalities is essential in order to promote the formulation and implementation of health policies that address both female and male needs, and concerns should be recognised in order to develop a

gender-sensitive framework that can be adopted to improve adherence to anti-psychotic medication in mental health care practice and research.

Furthermore, 61.8% of participants in this study belonged to ethnic minority subgroups. The overrepresentation of ethnic minorities in mental health statistics has been the subject of significant debate and research (Fenton et al., 1997; Fleischhacker et al., 2003; Pinikahana, 2005). There is a theoretical underpinning as to why there may be ethnic differences in adherence to medication regimes. Differences in communication styles may result in increased difficulties in conveying symptoms, side effects and concerns. Certain cultures may also display increased lack of acceptance of psychosis and anti-psychotic medication may be seen as irrelevant to the problem (Tsang et al., 2009). In order to improve the cultural sensitivity of mental health services, matching patients with professionals of the same ethnic origin is endorsed, as patients reportedly prefer treatment from professionals who shared their ethnic background (Ziguras et al., 2001).

Assessments and measures used may also have impacted findings. This study utilised the Duke-UNC Functional Social Support Questionnaire (Broadhead et al., 1988). The FSSQ is a sophisticated measure which has been validated to measure social support in a wide range of settings. However, social support is a capacious multidimensional concept which may differ for different individuals. Future research should focus on various forms of social support and its impact upon mental health. Practical issues such as financial support can often be overlooked although this may have a substantial impact and is an important form of support. Financial support may

have additional significance in the current economic climate, particularly in light of the recent changes to Disability Living Allowance and Personal Independence Payments which may affect individuals with psychosis (Duffy, 2013).

There is no “gold standard” evaluation method to monitor and assess adherence in research and clinical settings. In research, the choice of method has a significant impact on results. The most frequent methods utilised are based on indirect or subjective measures. Whereby either the patient, family members or clinicians are asked to rate the adherence levels. However, subjective measures of adherence are reported to have poor validity, with subjective self-report measures relying upon the accuracy of the individual completing the questionnaire. Clinicians are often reported to underestimate non-adherence (Haddad et al., 2014). This has led to an increase in the use of objective measures of adherence, such as the use of biological markers. The increased employment of anti-psychotic clozapine medication and the associated safeguards and guidelines involving regular white blood cell checks have coincided with the use of plasma drug levels to assess adherence (Coffey, 1999). Current findings suggest that plasma levels can vary depending on metabolism, tobacco use and other medications. Plasma levels only provide information of adherence of the days immediately prior to the test (Haddad et al., 2014). These issues make the assessment of adherence through plasma drug levels substantially polemic.

This study utilised the Medication Adherence Rating Scale (Thompson et al., 2000) as it addressed deficiencies of widely used measures, expanding upon previously used tools such as the Drug attitude inventory (DAI) and the Medication Adherence

Questionnaire (MAQ). The adherence measure utilised in this study provided a reliable measure as highlighted in the patient led groups prior to data collection. Future research should ensure that adherence is considered from a patient rather than clinical perspective and could potentially utilise several measures at the same time in order to evaluate which measure performs better in a population of individuals prescribed anti-psychotics.

19.1 Choice of theory.

This study utilised the Self-Regulation Model while exploring concepts surrounding adherence to anti-psychotic medication. While there is a growing body of research suggesting that the Self-Regulation Model's illness dimensions are appropriate for use in psychosis (Baines & Wittkowski, 2013), there are also other health psychology theories that could potentially have been useful in helping us understand the high rates of non-adherence in psychosis due to the unique nature of anti-psychotic treatment. Psychosis is not the only condition in which the side effects of treatment is considered to influence upon adherence. The impact of an individual's treatment-related beliefs on their adherence to the prescribed treatment programme are outlined in the Necessity-Concerns Framework (Horne & Weinman, 1999). The Necessity-Concerns Framework, is an increasingly influential multidimensional theory that emphasises the relationships between patients' necessity beliefs and concerns regarding medication, helps predict outcomes of medication adherence. According to the Necessity-Concerns Framework adherence is swayed by implicit judgments of one's personal need for the treatment (necessity beliefs) and their concerns regarding the possible unfavourable consequences of taking it. The Necessity-Concerns

Framework posits that individuals implicitly evaluate the costs and benefits of taking medication when deciding whether to adhere to it. Medication adherence will be enhanced if the individual's beliefs in the necessity of adhering to the medication exceed their concerns (Horne et al., 2013). Recent studies have attempted to utilise the Necessity-Concerns Framework across numerous illness domains, including asthma, HIV, cystic fibrosis, haemophilia, renal disease, hypertension, depression, diabetes, cardiac illnesses, cancer, and stroke survivors (Phillips, Diefenbach, Kronish, Negrón, & Horowitz, 2014). A meta-analytic review of the Necessity-Concerns Framework, exploring 93 studies involving 24,864 patients in 18 countries, covering 23 different long-term conditions, has provided support for its use in exploring adherence (Horne et al., 2013). It was argued that treatment-related beliefs predict adherence more strongly than socio-demographic variables, clinical variables, and other beliefs (Phillips et al., 2014). However, it remains to be seen if the predictive capacity of the Necessity-Concerns Framework can be successfully applied to adherence in psychosis where cognitive functioning is often impaired. Due to the unique nature of the condition and the often debilitating consequent side-effects of many anti-psychotic medications, it is also imperative that the measures used in such exploration be validated and apt for use amongst individuals diagnosed with psychosis. Nevertheless, the development of this framework has provided an important operational method for addressing non-adherence, highlighting adherence to treatment as a priority for research and practice.

Chapter 20. Conclusion.

The findings from this study serve to further the understanding of adherence to anti-psychotic medication and can help inform the focus of future interventions. Adherence to medication is a complex multi-factorial phenomenon, influenced by a number of parameters. Adherence to anti-psychotic medication presents with a unique set of challenges. Ultimately it is crucial to remember that adherence is the individual's choice. Involving patients in decisions about their treatment is critical to the success of their treatment. However, within clinical mental health settings professionals are often more authoritarian, occasionally opting to view patients as non-compliant which can cause distress, impede recovery and potentially breach human rights unless prioritising patients' best interests (Rethink Mental Illness, 2010).

Adherence to a medication programme is a behaviour and like all behaviours can be subject to change if the individual is willing. The role of the health care professional should be to work collaboratively with the patient to promote and encourage positive change. Numerous approaches have been proposed in an attempt to explain behaviour change and provide a framework for the development of interventions.

Encouraging adherence to prescribed medication can be challenging in numerous illnesses. However, individuals suffering from psychosis face a particular set of challenges to adherence that are unique to the condition. It is largely accepted that anti-psychotic treatment is effective in enhancing positive outcomes and the prevention

of relapse while reducing the severity of symptoms. Adherence to anti-psychotic medication has therefore been the subject of increasing research (Kao & Liu, 2010). The results of this study indicate that social support, and treatment control are determinants of adherence to anti-psychotic medication.

Unlike many physical health conditions, the symptoms of psychosis display considerable capriciousness between individuals. Conversely, the efficacy of anti-psychotic medication in the treatment of acute psychosis is well-established (Haddad et al., 2014). Non-adherence occurs in numerous chronic medical disorders, investigations into non-adherence amongst individuals suffering from psychosis is particularly challenging due to issues surrounding social isolation, lack of insight, co-morbid substance misuse and the severe side effects associated with anti-psychotics.

The potential consequences of non-adherence with medication for those suffering from psychosis are well documented, and include lower quality of life and increased risk of relapse, self-harm and rehospitalisation. This in turn is associated with longer in-patient treatments and associated costs. At a time when NHS budgets are facing increasing uncertainty and potential cuts, mental health services have borne the brunt of recent cuts in budget. This makes identifying the risk factors associated with non-adherence and attempting to eradicate or diminish these risks imperative as modifiable risk factors could be targeted by interventions (Velligan et al., 2009). The results of this study identify social support, treatment control and personal control as factors linked with adherence, with treatment control and personal control considered to be a determinant of adherence to anti-psychotic medication. As identified in the

discussion, there are a number of factors, which may have affected these findings. However, what is clear is that the potential for Health Psychology theories, frameworks and principles to not only scrutinise adherence within mental health settings but also develop behaviour change interventions to target identified risks is pertinent, and it is the hope of the author that this study will stimulate further research in this area and enhance the practice of Health Psychology within mental health settings.

Considering the overwhelming consequences of non-adherence, future research utilising Health Psychology theories should conduct further longitudinal studies exploring causes of non-adherence, concentrating on identifying risk factors, while developing interventions, approaches, strategies and planning to promote greater awareness of this phenomenon.

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APPENDICES

1. University Ethical Approval
2. Questionnaires utilised at PPI
3. Questionnaires utilised in study
4. Participant Recruitment Advert
5. Participant Information Sheet
6. Participant Consent Form
7. Participant Debrief Sheet

A. Ethical Approval

12th May 2015

Dear Faisal Satti

Reference: PSYCH (P/F) 14/15 155

Project title: Exploring predictors of adherence to anti-psychotic medication.

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee. Approval is conditional upon the following amendments:

- ☐ The student and supervisor should carry out risk assessments where appropriate.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee [REDACTED], in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality
- (c) Safeguarding issues relating to children and vulnerable adults
- (d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Karen Hunt
Departmental Administrator
Email: [REDACTED]
[REDACTED]

Katy Tapper
Chair
[REDACTED]

Email: [REDACTED]

B: PPI Measures

1. The Illness Perception Questionnaire (IPQ).
2. The Social Support Questionnaire (SSQ).
3. The Systematic Monitoring of Adverse events Related to Treatments (SMARTS).
4. The Medication Adherence Questionnaire (MAQ).
5. The Drug Attitude Inventory (DAI).
6. The Liverpool University Neuroleptic Side-Effect Rating Scale (LUNSERS).

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling Yes or No, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

I have experienced this symptom *since my illness*

This symptom is
related to my illness

| | | | | |
|---------------------------|------------|-----------|------------|-----------|
| Pain | Yes | No | Yes | No |
| Nausea | Yes | No | Yes | No |
| Breathlessness | Yes | No | Yes | No |
| Weight Loss | Yes | No | Yes | No |
| Fatigue | Yes | No | Yes | No |
| Stiff Joints | Yes | No | Yes | No |
| Sore Eyes | Yes | No | Yes | No |
| Headaches | Yes | No | Yes | No |
| Upset Stomach | Yes | No | Yes | No |
| Sleep Difficulties | Yes | No | Yes | No |
| Dizziness | Yes | No | Yes | No |
| Loss of Strength | Yes | No | Yes | No |

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

| | VIEWS ABOUT YOUR ILLNESS | STRONG LY DISA- GREE | DISA- GREE | NEI- THER AGR EE NOR DISA- GREE | AGREE | STRONL GY AGREE |
|-----------|--|-------------------------------------|-----------------------|--|--------------|--------------------------------|
| IP1 | My illness will last a short time | | | | | |
| IP2 | My illness is likely to be permanent rather than temporary | | | | | |
| IP3 | My illness will last for a long time | | | | | |
| IP4* | This illness will pass quickly | | | | | |
| IP5 | I expect to have this illness for the rest of my life | | | | | |
| IP6 | My illness is a serious condition | | | | | |
| IP7 | My illness has major consequences on my life | | | | | |
| IP8 | My illness is easy to live with | | | | | |
| IP10 | My illness strongly affects the way others see me | | | | | |
| IP11 | My illness has serious financial consequences | | | | | |
| IP13 * | My illness causes difficulties for those who are close to me | | | | | |
| IP17 | There is a lot which I can do to control my symptoms | | | | | |
| IP18 | What I do can determine whether my illness gets better or worse | | | | | |
| IP20 * | The course of my illness depends on me | | | | | |
| IP21 * | Nothing I do will affect my illness | | | | | |
| IP22 * | I have the power to influence my illness | | | | | |
| IP23 * | My actions will have no affect on the outcome of my illness | | | | | |
| IP26 | My illness will improve in time | | | | | |

| | | | | | | |
|-----------|--|--|--|--|--|--|
| IP27 | There is very little that can be done to improve my illness | | | | | |
| IP28 * | My treatment will be effective in curing my illness | | | | | |
| IP29 * | Negative effects of my illness can be prevented (avoided) by my treatment | | | | | |
| IP30 * | My treatment can control my illness | | | | | |
| IP31 * | There is nothing which can help my condition | | | | | |
| IP32 | The symptoms of my condition are puzzling to me | | | | | |

| | VIEWS ABOUT YOUR ILLNESS | STRONG LY DISA- GREE | DISA- GREE | NEI- THER AGR EE NOR DISA- GREE | AGREE | STRONL GY AGREE |
|-----------|---|----------------------------|---------------|---|-------|-----------------------|
| IP33 | My illness is a mystery to me | | | | | |
| IP34 * | I don't understand my illness | | | | | |
| IP35 * | My illness doesn't make any sense to me | | | | | |
| IP36 * | I have a clear picture or understanding of my condition | | | | | |
| IP37 | The symptoms of my illness change a great deal from day to day | | | | | |
| IP38 * | My symptoms come and go in cycles | | | | | |
| IP39 * | My illness is very unpredictable | | | | | |
| IP41 * | I go through cycles in which my illness gets better and worse. | | | | | |
| IP44 | I get depressed when I think about my illness | | | | | |
| IP45 * | When I think about my illness I get upset | | | | | |
| IP46 * | My illness makes me feel angry | | | | | |
| IP47 * | My illness does not worry me | | | | | |
| IP48 * | Having this illness makes me feel anxious | | | | | |
| IP50 * | My illness makes me feel afraid | | | | | |

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your

own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

| | POSSIBLE CAUSES | STRONG LY DISA- GREE | DISA- GREE | NEI- THER AGRE E NOR DISA- GREE | AGREE | STRONL GY AGREE |
|------|--|----------------------------|---------------|--|-------|-----------------------|
| C1 | Stress or worry | | | | | |
| C2 | Hereditary - it runs in my family | | | | | |
| C3 | A Germ or virus | | | | | |
| C4 | Diet or eating habits | | | | | |
| C5 | Chance or bad luck | | | | | |
| C6 | Poor medical care in my past | | | | | |
| C7 | Pollution in the environment | | | | | |
| C8 | My own behaviour | | | | | |
| C9 | My mental attitude e.g. thinking about life negatively | | | | | |
| C10 | Family problems or worries | | | | | |
| C11* | Overwork | | | | | |
| C12* | My emotional state e.g. feeling down, lonely, anxious, empty | | | | | |
| C13* | Ageing | | | | | |
| C16* | Accident or injury | | | | | |
| C17* | My personality | | | | | |
| C18* | Altered immunity | | | | | |

In the table below, please list in rank-order the three most important factors that you now believe caused **YOUR ILLNESS**. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

- 1.
- 2.
- 3.

2. SARASON SOCIAL SUPPORT QUESTIONNAIRE (Short Form) SSQSR

INSTRUCTIONS:

The following questions ask about people in your life who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, who you can count on for help or support in the manner described. Write the person's initials and their relation to you (see example). Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have.

If you have no support for a question, circle the words "No one," but still rate your level of satisfaction. Do not list more than nine people per question.

Please answer all the questions the best you can. All your responses will be kept confidential.

Example:

Who do you know who you can trust with information that can get you into trouble?

No one 1.) T.N. (brother) 4.) D.N. (father) 7.)
2.) L.M. (friend) 5.) W.T. (employer) 8.)
3.) R.S. (friend) 6.) 9.)

How satisfied?

6 – very 5 - fairly 4 - a little 3 - a little 2 - fairly 1- very satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

1. Who can you really count on to be dependable when you need help?

| | | | |
|-----|-----|---|-----|
| No | 1.) | 4 | 7.) |
| one | | . | |
| | |) | |
| | 2.) | 5 | 8.) |
| | | . | |
| | |) | |
| | 3.) | 6 | 9.) |
| | | . | |
| | |) | |

2. How satisfied?

| | | | | | |
|-----------|------------|--------------|--------------|--------------|--------------|
| 6 - very | 5 - fairly | 4 - a little | 3 - a little | 2 - fairly | 1- very |
| Satisfied | satisfied | satisfied | dissatisfied | dissatisfied | dissatisfied |
| | | | | fied | isfied |

3. Who can you really count on to help you feel more relaxed when you are under pressure or tense?

| | | | |
|--------|-----|---|-----|
| No one | 1.) | 4 | 7.) |
| | | . | |
| | |) | |
| | 2.) | 5 | 8.) |
| | | . | |
| | |) | |
| | 3.) | 6 | 9.) |
| | | . | |
| | |) | |

4. How satisfied?

| | | | | | |
|-----------|------------|--------------|--------------|--------------|--------------|
| 6 - very | 5 - fairly | 4 - a little | 3 - a little | 2 - fairly | 1 - very |
| Satisfied | satisfied | satisfied | dissatisfied | dissatisfied | dissatisfied |

5. Who accepts you totally, including both your worst and best points?

| | | | |
|--------|-----|---|-----|
| No one | 1.) | 4 | 7.) |
| | | . | |
| | |) | |
| | 2.) | 5 | 8.) |
| | | . | |
| | |) | |
| | 3.) | 6 | 9.) |
| | | . | |
| | |) | |

6. How satisfied?

| | | | | | |
|-----------|------------|--------------|--------------|--------------|--------------|
| 6 - very | 5 - fairly | 4 - a little | 3 - a little | 2 - fairly | 1 - very |
| Satisfied | satisfied | satisfied | dissatisfied | dissatisfied | dissatisfied |

7. Who can you really count on to care about you, regardless of what is happening to you?

| | | | |
|--------|-----|---|-----|
| No one | 1.) | 4 | 7.) |
| | | . | |
| | |) | |
| | 2.) | 5 | 8.) |
| | | . | |
| | |) | |
| | 3.) | 6 | 9.) |
| | | . | |
| | |) | |

8. How satisfied?

| | | | | | |
|-----------|------------|--------------|--------------|--------------|--------------|
| 6 - very | 5 - fairly | 4 - a little | 3 - a little | 2 - fairly | 1 - very |
| Satisfied | satisfied | satisfied | dissatisfied | dissatisfied | dissatisfied |

9. Who can you really count on to help you feel better when you are feeling down-in-the-dumps?

| | | | |
|--------|-----|---|-----|
| No one | 1.) | 4 | 7.) |
| | | . | |
| | |) | |
| | 2.) | 5 | 8.) |
| | | . | |
| | |) | |
| | 3.) | 6 | 9.) |
| | | . | |
| | |) | |

10. How satisfied?

| | | | | | |
|-----------|------------|--------------|--------------|--------------|--------------|
| 6 - very | 5 - fairly | 4 - a little | 3 - a little | 2 - fairly | 1 - very |
| Satisfied | satisfied | satisfied | dissatisfied | dissatisfied | dissatisfied |

11. Who can you count on to console you when you are very upset?

| | | | |
|--------|-----|---|-----|
| No one | 1.) | 4 | 7.) |
| | | . | |
| | |) | |
| | 2.) | 5 | 8.) |
| | | . | |
| | |) | |
| | 3.) | 6 | 9.) |
| | | . | |
| | |) | |

6. How satisfied?

| | | | | | |
|-----------|------------|--------------|--------------|--------------|--------------|
| 6 - very | 5 - fairly | 4 - a little | 3 - a little | 2 - fairly | 1 - very |
| Satisfied | satisfied | satisfied | dissatisfied | dissatisfied | dissatisfied |

TO SCORE SSQSR:

1. Count the total number of people for each of the odd-numbered items. Add the total together (Max = 54). Divide by 6 per item SSQ Number Score, or SSQN.
2. Add the total satisfaction scores for the 6 even-numbered items (Max = 36). Divide by 6 per item SSQ Satisfaction Score or SSQS.
3. You can also compute a Family score and a Non-Family score by using the method in #1 for all people describes as family members, or not described as family members respectively.

3.SMARTS

Systematic Monitoring of Adverse events Related to TreatmentS

Instructions:

We want to be sure that you are receiving the best treatment, and would like to check whether you have any problems which may result from taking your medications.

Please circle any of the following items that trouble you, so that your doctor or nurse can discuss them with you.

Are you troubled by:

1. Difficulties in your movement such as shaking, stiffness or muscle aches?
2. Changes in your weight or appetite?
3. Problems with your sex life?
4. Changes in your periods or changes in your breasts?
5. Dizziness or light-headedness?
6. Tiredness or sleepiness?
7. Restlessness or feeling fidgety?
8. Constipation, diarrhoea, nausea, stomach problems or dry mouth?
9. Difficulty passing water or passing water very frequently?
10. Problems with your concentration or memory?
11. Feeling anxious or depressed?
12. Any other problems which you think may be related to your medication?

Please
state _____

4. Medication Adherence Questionnaire (MAQ)

| | | |
|---|-------------|--------------|
| <p>You indicated that you are taking medication for your (identify health concern, such as “high blood pressure”). Individuals have identified several issues regarding their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your [health concern] medication. Interviewers may self identify regarding difficulties they may experience concerning medication-taking behavior.</p> | | |
| <p>(Please circle the correct number)</p> | | |
| | No=0 | Yes=1 |
| 1. Do you sometimes forget to take your [health concern] pills? | | |
| 2. People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your [health concern] medicine? | | |
| 3. Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it? | | |
| 4. When you travel or leave home, do you sometimes forget to bring along your [health concern] medication? | | |
| 5. Did you take your [health concern] medicine yesterday? | | |
| 6. When you feel like your [health concern] is under control, do you sometimes stop taking your medicine? | | |
| 7. Taking medication everyday is a real inconvenience for some people. Do you ever feel hassled about sticking to your blood pressure treatment plan? | | |
| <p>8. How often do you have difficulty remembering to take all your medications? (Please circle the correct number)</p> <p>Never/Rarely.....0</p> <p>Once in a while.....1</p> <p>Sometimes.....2</p> <p>Usually.....3</p> <p>All the time.....4</p> | | |

Source: Morisky DE, Ang A, Krousel-Wood M, Ward H. Predictive Validity of a Medication Adherence Measure for Hypertension Control. *Journal of Clinical Hypertension* 2008; 10(5):348-354.

For additional information, contact: Donald E. Morisky, Sc.D., M.S.P.H., Sc.M., e-mail: dmorisky@ucla.edu; phone: (310) 825-8508

5. DAI-10 questionnaire

| Q u e s t i o n | | Answer (True/False) * |
|--|--|---------------------------|
| 1 | For me, the good things about medication outweigh the bad | T / F |
| 2 | I feel strange, "doped up", on medication | T / F |
| 3 | I take medications of my own free choice | T / F |
| 4 | Medications make me feel more relaxed | T / F |
| 5 | Medication makes me feel tired and sluggish | T / F |
| 6 | I take medication only when I feel ill | T / F |
| 7 | I feel more normal on medication | T / F |
| 8 | It is unnatural for my mind and body to be controlled by medications | T / F |
| 9 | My thoughts are clearer on medication | T / F |
| 10 | Taking medication will prevent me from having a breakdown | T / F |
| If you have any further comments about medication or this questionnaire, please write them below | | |

T = True, F = False

*Answers shown in **bold** are scored +1; answers in normal font are scored -1

Lungers



Name: _____

Assessment No.: _____

Assessment Date: _____

Please indicate how much you have experienced each of the following symptoms in **the last month** by ticking the appropriate boxes.

| | Not At All | Very Little | A Little | Quite a Lot | Very Much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1.Rash | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2.Difficulty staying awake during the day | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3.Runny nose | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4.increased dreaming | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5.Headaches | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6.Dry mouth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7.Swollen or tender chest | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8.Chilblains | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9.Difficulty in concentrating | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10.Constipation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11.Hair loss | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12.Urine darker than usual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13.Period problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14.Tension | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15.Dizziness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16.Feeling sick | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Not At All | Very Little | A Little | Quite a Lot | Very Much |
|----------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 17.Increased sex drive | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18.Tiredness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19.Muscle stiffness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20.Palpitations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21.Difficulty remembering things | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22.Losing weight | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23.Lack of emotions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24.Difficulty achieving climax | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25.Weak fingernails | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26.Depression | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27.Increased sweating | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28.Mouth ulcers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29.Slowing of movements | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30.Greasy skin | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31.Sleeping too much | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32.Difficulty passing water | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33.Flushing of face | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34.Muscle spasms | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 35.Sensitivity to sun | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36.Diarrhoea | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37.Over-wet drooling mouth | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 38.Blurred vision | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Not At All | Very Little | A Little | Quite a Lot | Very Much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 39.Putting on weight | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 40.Restlessness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 41.Difficulty getting to sleep | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 42.Neck muscles aching | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 43.Shakiness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 44.Pins and needles | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 45.Painful joints | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 46.Reduced sex drive | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 47.New or unusual skin marks | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 48.Parts of body moving of own accord. <i>For example foot moving up and down.</i> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 49.Itchy skin | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 50.Periods less frequent | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 51.Passing a lot of water | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

C- Measures Used in Research

1. Medication Adherence Rating Scale (MARS).
2. Drug Abuse Screening Test (DAST-10).
3. Glasgow Anti-Psychotic Side Effect Scale (GASS).
4. Duke Functional Social Support Scale (FSSQ).

MARS questionnaire

Question Answer

1. Do you ever forget to take your medication? Yes / No
2. Are you careless at times about taking your medication? Yes / No
3. When you feel better, do you sometimes stop taking your medication? Yes / No
4. Sometimes if you feel worse when you take the medication, do you stop taking it? Yes / No
5. I take my medication only when I am sick Yes / No
6. It is unnatural for my mind and body to be controlled by medication Yes / No
7. My thoughts are clearer on medication Yes / No
8. By staying on medication, I can prevent getting sick. Yes / No
9. I feel weird, like a 'zombie' on medication Yes / No
10. Medication makes me feel tired and sluggish Yes / No

Drug Use Questionnaire (DAST-10)

Participant No: _____

Test Date: _____

Score: _____

Preliminary Comments

Adapted from language provided by Dr. Harvey Skinner (January 5, 2009)

The following questions concern your potential involvement with drugs other than alcohol. When you answer the questions, remember that the term “drug abuse” does not include alcohol. Instead, it refers to your use of prescribed or over the counter drugs in excess of the recommended dosage. For example, if you were given a prescription for pain killers, but took more than you were supposed to, that would be included. The phrase “drug abuse” also includes *any* non-medical drug use, including illegal drugs. This includes substances like marijuana, valium, cocaine, amphetamines, LSD, and heroin. Remember that the term “drug abuse” does not include alcohol. If you have difficulty with a statement, then choose the response that is mostly right.

Do you understand?

Questions

These questions refer to the past 12 months.

**Circle the
Response**

- | | | |
|--|-----|----|
| 1. Have you used drugs other than those required for medical reasons? | Yes | No |
| 2. Do you abuse more than one drug at a time? | Yes | No |
| 3. Are you always able to stop using drugs when you want to? | Yes | No |
| 4. Have you had “blackouts” or flashbacks” as a result of drug use? | Yes | No |
| 5. Do you ever feel bad or guilty about your drug use? | Yes | No |
| 6. Does your spouse (or parents) ever complain about your involvement with drugs? | Yes | No |
| 7. Have you neglected your family because of your use of drugs? | Yes | No |
| 8. Have you engaged in illegal activities in order to obtain drugs? | Yes | No |
| 9. Have you ever experienced withdrawal symptoms (felt sick) when you stopped taking drugs? | Yes | No |
| 10. Have you had medical problems as a result of your drug use (e.g. memory loss, hepatitis, convulsions, bleeding, etc.)? | Yes | No |

Duke–UNC Functional Social Support Questionnaire (FSSQ)

Here is a list of some things that other people do for us or give us that may be helpful or supportive. Please read each statement carefully and place an 'X' in the column that is closest to your situation. Give only 1 answer per row.

| | 5 | 4 | 3 | 2 | 1 |
|---|----------------------------|-----------------------------------|------------------------------|---------------------------|--------------------------------|
| | As much as I would like | Almost as much as I would like | Some, but would like more | Less than I would like | Much less than I would like |
| 1. I have people who care what happens to me. | | | | | |
| 2. I get love and affection. | | | | | |
| 3. I get chances to talk to someone about prob- lems at work or with my housework. | | | | | |
| 4. I get chances to talk to someone I trust about my personal or family problems. | | | | | |
| 5. I get chances to talk about money matters. | | | | | |

| | | | | | |
|---|--|--|--|--|--|
| 6. I get invitations to go out and do things with other people. | | | | | |
| 7. I get useful advice about important things in life. | | | | | |
| 8. I get help when I am sick in bed. | | | | | |

Source: adultmeducation.com

Glasgow Antipsychotic Side-effect Scale (GASS)

Name: _____ Age: _____ Sex: M / F

Please list current medication and total daily doses below:

This questionnaire is about how you have been recently. It is being used to determine if you are suffering from excessive side effects from your antipsychotic medication.

Please place a tick in the column which best indicates the degree to which you have experienced the following side effects. Tick the **end** box if you found that the side effect distressed you.

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| <i>Over the past week:</i> | <i>Never</i> | <i>Once</i> | <i>A few times</i> | <i>Everyday</i> | <i>Tick this box if distressing</i> |
|--|--------------|-------------|--------------------|-----------------|-------------------------------------|
| 1. I felt sleepy during the day | | | | | |
| 2. I felt drugged or like a zombie | | | | | |
| 3. I felt dizzy when I stood up and/or have fainted | | | | | |
| 4. I have felt my heart beating irregularly or unusually fast | | | | | |
| 5. My muscles have been tense or jerky | | | | | |
| 6. My hands or arms have been shaky | | | | | |
| 7. My legs have felt restless and/or I couldn't sit still | | | | | |
| 8. I have been drooling | | | | | |
| 9. My movements or walking have been slower than usual | | | | | |
| 10. I have had, or people have noticed uncontrollable movements of my face or body | | | | | |
| 11. My vision has been blurry | | | | | |
| 12. My mouth has been dry | | | | | |
| 13. I have had difficulty passing urine | | | | | |
| 14. I have felt like I am going to be sick or have vomited | | | | | |
| 15. I have wet the bed | | | | | |
| 16. I have been very thirsty and/or passing urine frequently | | | | | |
| 17. The areas around my nipples have been sore and swollen | | | | | |
| 18. I have noticed fluid coming from my nipples | | | | | |
| 19. I have had problems enjoying sex | | | | | |
| 20. <u>Men only</u> : I have had problems getting an erection | | | | | |

| Tick yes or no for the following questions about the last three months | <i>No</i> | <i>Yes</i> | <i>Tick this box if distressing</i> |
|--|-----------|------------|-------------------------------------|
| 21. <u>Women only</u> : I have noticed a change in my periods | | | |
| 22. <u>Men and women</u> : I have been gaining weight | | | |



**Department of Psychology
City University London**

**PARTICIPANTS NEEDED FOR
RESEARCH IN HEALTH PSYCHOLOGY**

We are looking for volunteers to take part in a study investigating determinants of adherence to anti-psychotic medication.

What is the purpose of this research?

People prescribed anti-psychotic medication commonly report non-adherence to their medication. The purpose of this study is to test the principles of Health Psychology in determining adherence to anti-psychotic medication.

Why have I been chosen?

You are invited to participate in this study if you are aged 18 or above, take anti-psychotic medication and reside in the community. Participants are being recruited from a range of locations including online forums, social media and local resources. We will be aiming to recruit 100 people in total.

Do I have to take part?

No, participation in this research is completely voluntary. If you decide to take part, then you are still free to withdraw from the study, without giving a reason and without any negative consequences.

For more information about this study, or to take part,
please contact:

Faisal Satti / Dr Angeliki Bogosian
Psychology Department
at



What happens if I decide to take part?

You would be asked to complete 5 anonymous questionnaires and then the same five questionnaires again in one year's time.

Your participation would involve 2 sessions, each of which is approximately 30 minutes.

What are the possible benefits of taking part?

If found to be helpful, the results of the study materials will be developed further and used in future trials to understand the factors that help people adhere to anti-psychotic medication.

Will participation be kept confidential?

Yes, the data you provide will be accepted in complete confidence and will not be disclosed beyond the researchers involved. All data will be reported anonymously in any future publication of the results.

This study has been reviewed by, and received ethics clearance through the Psychology Research Ethics Committee, City University London [PSYCH (P/F) 14/15 155].

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on [REDACTED]
[REDACTED]

Thank you very much for taking the time to read through this information

An investigation into determinants of adherence to anti-psychotic medication.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

You are being invited to take part in a study on anti-psychotic treatment. The research is done to better understand issues around taking anti-psychotic medication. If you decide to take part I would be very grateful if you could take some time out to fill the attached questionnaires that will take approximately 30 minutes to complete.

Why have I been invited?

Adults who are living in the community, have been diagnosed with schizophrenia, and are currently self-medicating are invited to take part.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in part or the entire project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

You would be asked to complete 3 anonymous questionnaires and then the same three questionnaires again in one years' time. Your participation would involve 2 sessions, each of which will take approximately 30 minutes. The questionnaires can be completed in a time and place convenient to yourself.

What do I have to do?

Attached is a consent form, three questionnaires and a debrief sheet, please read through and sign the consent form as a formal agreement in taking part in this study prior to filling out the questionnaires. Moreover, if you need/want more information regarding the study please do not hesitate to ask.

What are the possible disadvantages and risks of taking part?

This study will involve questions about illegal recreational drugs. This is to explore whether illicit substance use is a predictor to adherence to anti-psychotic medication. Your responses will be anonymised and your details will remain confidential, so we would encourage you to answer truthfully. Neither City University, nor the researchers undertaking this study, condone the use of illicit drugs. Taking part in this study should therefore not be seen as providing any support or encouragement for the use of illegal drugs.

If the participation caused any emotional discomfort or if you would like to talk to someone or find out information about where you can receive help for any health related problems you will be provided with details of registered agencies that may be useful to you.

What are the possible benefits of taking part?

We cannot guarantee that you will benefit from taking part in this study. But the results of this study will help us better understand issues around taking medication and what makes it easier or more difficult.

What will happen when the research study stops?

All data collected from the participants will be anonymized and securely stored with only the researchers having access to it. If the project is stopped all collected data will be destroyed

Will my taking part in the study be kept confidential?

All data is kept strictly confidential, only the researcher will have access to your personal information which will immediately be anonymised. However, the researcher may have to breach confidentiality if concerned that someone could be at risk of harm. Confidentiality may be broken in the following circumstances: If a participant tells the researcher something that causes significant concern, for example that they plan to hurt themselves or others.

What will happen to the results of the research study?

The results will be written up as part of a professional doctorate in health psychology. The results may also be result in possible future publications. If this occurs complete anonymity of all participants will be maintained.

What will happen if I don't want to carry on with the study?

You are free to stop and withdraw yourself from the study within two weeks after completing the questionnaires and any data collected will be destroyed.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone [REDACTED]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Exploring predictors of adherence to anti-psychotic medication.

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London, EC1V 0HB
[REDACTED]

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London *Psychology* Research Ethics Committee, [*insert ethics approval code here*].

Further information and contact details: If you would like any further information any inquiries about the research can be made to;

Faisal Satti / Dr Angeliki Bogosian Psychology Department at [REDACTED] or Email: [REDACTED]
[REDACTED]

Thank you for taking the time to read this information sheet.

Title of Study: **Investigating determinants of adherence to anti-psychotic medication.**

Ethics approval code: [PSYCH (P/F) 14/15 155]

Please initial box

| | | |
|----|--|--|
| 1. | <p>I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.</p> <p>I understand this will involve:</p> <ul style="list-style-type: none"> <input type="checkbox"/> completing questionnaires asking me about adherence to medication. <input type="checkbox"/> making myself available to complete the same questionnaires again in one years' time. | |
| 2. | <p>This information will be held and processed for the following purpose(s):</p> <ul style="list-style-type: none"> <input type="checkbox"/> to compare questionnaires measuring adherence <input type="checkbox"/> to explore issues surrounding adherence from Health Psychology perspective | |
| 3. | <p>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.</p> | |
| 4. | <p>I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.</p> | |
| 5. | <p>I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.</p> | |
| 6. | <p>I agree to take part in the above study.</p> | |

Name of Participant

Signature

Date

Name of Researcher

Signature

Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.



Investigating determinants of adherence to anti-psychotic medication.

DEBRIEF INFORMATION

Thank you for taking part in this study and completing the questionnaires. Now that it's finished we'd like to explain the rationale behind the work.

We are going to look into the issue of taking prescribed anti-psychotic medication by adults living in the community. Your participation will be valuable in raising awareness of a significant topic that may improve further understandings of this area.

I would like to remind you that all of your data will be kept strictly confidential and will be anonymised. If for any reason you would like to withdraw your data you can do so within two weeks of completing the questionnaires. If you have any queries, then contact myself, or the academic supervisor Dr Angeliki Bogosian (contact details at the bottom of the page).

The study has been conducted under supervision of City University London and will contribute towards the researchers Doctorate in Health Psychology. It has been conducted according to the Code of Conduct, Ethical Principles & Guidelines of The British Psychological Society.

If the participation caused any emotional discomfort or if you would like to talk to someone or find out information about where you can receive help for any health related problems the following registered agencies may be useful to you:

The Independent Mental Capacity Advocate Service

The statutory advocacy service under the Mental Capacity Act:

24 hour confidential emotional support, tel. **0845 3302900**, e-mail: customer services@publicguardian.gsi.gov.uk; web: www.publicguardian.gov.uk

NHS Direct:

The NHS 24 hour helpline, tel. **0845 4647**, web: www.nhsdirect.nhs.uk

Samaritans:

The 24 hour confidential emotional support, tel. **08457 90 90 90**, web: www.samaritans.org

Talk to Frank:

This study involved questions about illegal recreational drugs. All illegal drugs tend to be harmful, and some can be very damaging. We advise all drug users to quit using drugs, or at least to limit their consumption.

Further valuable information about drug effects: tel. **0800 776 600**, web: www.talktofrank.com

Or if the research has raised any concerns you might find it useful to contact your GP, Key Worker or an appropriate mental health professional e.g. your social worker or care coordinator.

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Researcher: Faisal Satti, e-mail: [REDACTED]

Supervisor: Dr Angeliki Bogosian, e-mail: [REDACTED]
[REDACTED]

We will be happy to answer any questions or receive any feedback.

Ethics approval code: [PSYCH (P/F) 14/15 155.]

SECTION C

PROFESSIONAL
PRACTICE

CORE UNIT 1
DHP 061

GENERIC PROFESSIONAL COMPETENCE

Unit 1.1 Implement and maintain systems for legal, ethical and professional standards in applied psychology.

During my time as a trainee Health Psychologist, I was employed in a community-based mental health setting. I will outline and reflect upon my professional practice within my post as the manager of a community project for forensic mental health patients. I will reflect upon my professional development as an applied Health Psychologist and the application of psychological principles throughout my professional practice. I will also provide an account of how I have enhanced a range of skills, including; conducting research and systematic reviews, developing consultancies, implementing behaviour change, teaching and training, providing feedback, psychological advice and guidance to others in addition to maintaining systems for legal ethical and professional practices in applied psychology.

1.1a Establish, maintain and review systems for the security and control of information.

Prior to commencing the training, I sought advice from various professionals including the course leader of a professional doctorate in Health Psychology programme. I wanted to have a clear understanding of the requirements and practicalities of undertaking the process. My main concern was whether it was practical to attempt combining the training, with my role as a manager specialising in forensic mental health patients. I felt passionately that incorporating Health Psychology principles

with a client group where little focus was placed upon physical health, would potentially be of immense practical benefit. The advice that I received made it apparent that the amount of client contact, coupled with the scope and autonomy that I had within my role, would be a considerable advantage with regard to the ease of directly applying theory within my professional practice. Although I was not supervised by an applied Health Psychologist within my professional setting, the Health Psychology supervision that I would receive as part of the professional doctorate, would be of immense practical benefit. The fact that establishing, maintaining and reviewing systems for the security and control of information was already a large part of my role, provided me with an understanding of the protocols required to ensure legal, ethical and professional standards.

Throughout my employment, I have been required to establish, maintain and review systems for the security and control of information. Maintaining confidentiality across organisations is a key factor. I initially work with service users while they remain inpatients within secure forensic wards and help them transition post discharge. Ultimately, facilitating their reintegration into society. I have ensured that the storage, access and transfer of all patient information was in accordance with the Data Protection Act 1988. Overall, the aims of my professional practice included providing a safe environment in which the patient has as much control over their lives as possible. Enabling them to achieve the maximum degree of independence while retaining their dignity. Providing each individual with an opportunity to build new skills for life and adapt old ones. I looked to develop a therapeutic programme under the care programme approach, relevant to individual needs, while facilitating each to function at their potential.

I was registered with The Care Quality Commission (CQC) who regulate all registered activities that I managed. This process involves in-depth unannounced inspections. During the professional practice that makes up this portfolio, I received an unannounced inspection by a team of four CQC inspectors on the 18th of October 2016. By this point, I had been practising as a trainee Health Psychologist for two years. The resulting inspection report provides an in-depth account of my professional practice (please refer to Practice Log). While completing the research thesis and behaviour change intervention, I ensured that all BPS and HCPC ethical guidelines regarding participant data protection were met. All information was securely stored on an encrypted USB and in locked filing cabinets. Participants were reminded that participation was voluntary, would not have any bearing on any other treatment and reminded that they could withdraw at any stage if they choose to do so.

1.1b Ensure compliance with legal, ethical and professional practices for self and others.

In my role as the Registered Manager, I specialised in providing support to forensic clients who were subject to various Ministry of Justice ascribed conditions. As the registered individual with CQC, I am charged with overall responsibility for the legal, ethical and professional running of the unit. The CQC has in-depth regulatory guidelines for how this should take place as outlined in CQC (Registration) Regulations 2009 (as amended March 2015). These guidelines are informed by the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

Within my role, I was required to develop and implement all policies and procedures ensuring that they meet legal, ethical and professional standards not just of the CQC but also of the local authority and relevant NHS organisations. Many of the principles that underpin these standards are similar to BPS ethical guidelines. Thus, I have had ample opportunity to meet these requirements throughout my professional practice. I have also had the responsibility of supervising staff to ensure that these standards are met by others.

I ensured that compliance with legal, ethical and professional practices for both myself and others by working within CQC Regulations. Furthermore, as a member of both the British Psychological Society (BPS) and the Division of Health Psychology (DHP), I made certain to adhere to the Society's Code of Ethics and Conduct (2006). Throughout my professional practice and in the supervision of others, I endeavoured to meet the values that underpin the ethical principles of respect, responsibility, competency and integrity which form the code. The policies and procedures that I have developed to ensure compliance reflect this. Furthermore, the process of successfully obtaining ethical approval ensured that my research conformed to the University's ethical committee guidelines.

1.1c Establish, implement and evaluate procedures to ensure competence in psychological practice and research.

Before commencing the training, I had taken the time to evaluate how I would attempt to establish, implement, meet and subsequently evaluate the various competencies and I developed a time-scale for achieving this. It became apparent that the nature of my professional role would be of enormous benefit due to the existing level of psychological practice and direct patient contact. In my discussions with professionals who had completed the training, I was keen to ascertain what was felt to be a reasonable timescale to achieve competence. I was consistently informed that stability within the trainee's work setting was a key factor to consider regarding duration for the overall process. I, therefore, became extremely apprehensive when a month after commencing the training I became aware that my organisation was the subject of a change of ownership. However, the subsequent changes in structure culminated with an increased level of professional autonomy within my role, affording me the scope to establish, implement and evaluate procedures in accordance with the training that I was receiving as part of the programme. I was able to design and implement competencies in line with this training and the support and guidance that I received from both my Professional and Academic Supervisors. This ensured that the competence of my psychological practice was robustly evaluated and reflected upon. With changes and alterations made where necessary. A prime example of this is provided by the behaviour change competency which was chronologically the first competence that I undertook. As I had extensive experience of designing and implementing behaviour change interventions within mental health settings, I felt comfortable when setting up the competence. However, when evaluating procedures as part of my professional practice as a trainee Health Psychologist, I realised that I needed to structure and design sessions in a very different way to ensure that in-depth formulations, assessments and Health Psychology evaluations were conducted in a

way which is unique to the profession of an applied Health Psychologist. Through reflection and the guidance of my supervisors, I was able to achieve this.

Further opportunities to establish, implement and evaluate procedures to ensure competence, were provided by the research practice conducted as part of the training. My research thesis and systematic review provide evidence that my work was conducted in a robust, planned manner. I developed a protocol to establish procedures for the systematic review. To develop effective appraisal of the quality and validity of studies reviewed, a scoring system was initially devised. However, this was reviewed during supervision and a joint decision on how to conduct quality assessment was made. Progression was regularly reviewed with my supervisor to ensure the quality of the systematic review process.

The research and systematic review have been adapted and are currently being peer-reviewed for publication. I believe that the process of peer-review will add an additional evaluation of the research and provides an excellent opportunity for the dissemination of findings.

Unit 1.2 Contribute to the continuing development of self as a professional applied psychologist.

Upon commencing the programme, I strived to maximise every opportunity of self-development. Initially, I felt that my previous professional experience and first-hand

practical knowledge had provided me with an understanding of direct client contact and behaviour, which was useful in my academic endeavours. However, the longer I spent on the course furthering my development, the more I subsequently found the reverse to be true. Ultimately, I increasingly discovered that my training altered my professional practice when working with clients, as I progressively incorporated more advanced techniques and methods. Reflecting on my practice, through practice logs and discussions with supervisors and peers, also helped me recognise areas where I could improve. This enabled me to reflect on whether the work I was conducting for the Health Psychology competencies had the effect I was looking for and elements that I could improve.

1.2a Establish, evaluate and implement processes to develop oneself professionally.

The stage two training at City, University of London has provided numerous opportunities to establish, evaluate and implement processes for professional development. Competency-based workshops helped supplement training, and the application of psychological models within the competencies provided a framework to contextualise theoretical perspectives in an applied setting. I attended all of the Health Psychology doctorate workshops including ethics, consultancies, teaching and training, research methods, CBT, Motivational Interviewing and Systematic reviews. All of which helped enhance my professional development. I took advantage of numerous other forms of development including being awarded a bursary for a comprehensive training programme provided by SCCH Health Psychology Consulting LLP-

“Health Psychology Interventions in Practice” (Please refer to Practice Log). This training programme was of immense benefit as it was conducted by experienced Applied Health Psychologists who were able to provide numerous examples from their professional backgrounds and the focus was on the practical application of the discipline. The Training provided by the SCCH afforded an invaluable insight into the development and implementation of Health Psychology interventions. It bestowed a core understanding of implementing the science and evidence base of Health Psychology and Health Behaviour Change into the world of person-centred healthcare. I also attended conferences and completed several work-based training programmes to broaden my skills (Please refer to Practice Log).

Throughout the training, I have become increasingly involved in both the design and delivery of interventions. However, it became apparent that many Health Psychologists work exclusively in academia or research. Others have found employment in roles where they are not primarily delivering Health Psychology interventions. Relatively few Health Psychologists' primary role involves directly delivering person-centred interventions to patients within clinical settings. As a trainee working with forensic mental health patients, I feel it is important to distinguish between the ways that clinical and Health Psychologists go about this. I found the Health Psychology training of immense benefit in helping me develop professionally, as it provided first-hand accounts and examples of putting Health Psychology theory into practice. As a professional working within mental health, the training was of additional value as it outlined the challenges of applied professional practice. It explored the issues and complications that can arise in practical applications and outlined how to address and overcome these issues. Overall, the doctorate training was a valuable exercise

in helping to further my understanding of implementing the science and evidence base of Health Psychology and Health Behaviour Change in person-centred healthcare and helped inform my professional development.

1.2b Elicit, monitor and evaluate knowledge and feedback to inform practice.

During the training, I actively sought to regularly obtain feedback from a variety of sources. Initially, I would seek advice from my supervisor on aspects where I was unclear. However, as the training progressed, I augmented confidence in my ability to seek feedback from others. After jointly agreeing upon a supervision plan with my academic supervisor, we would meet regularly, and I would monitor, evaluate and reflect upon the feedback provided. Initial supervision focused on exploring approaches, concepts and ideas in relation to conducting competencies. I became adept at applying constructive feedback to enhance my skills and incorporate best practice.

As I began implementing the competencies, I was afforded with greater opportunities to elicit, monitor and evaluate knowledge and feedback to inform practice. Some of this feedback has been included as part of this portfolio. For example, during each training session I carried out, I designed and handed out feedback forms for all participants. I would evaluate these forms and altered subsequent training sessions accordingly. Similarly, after evaluating the feedback following the first lecture that I carried out at the University (refer to practice log), I adapted my approach for

subsequent lectures. It is a source of pride that the feedback that I received during the training was largely positive and appeared to improve as the training developed.

1.2c Organise, clarify and utilise access to competent consultation and advice.

I used and accessed competent consultation and advice from various sources. This included both my academic and professional supervisors, my line manager, work colleagues, professionals and specialists from various disciplines such as clinical psychology and psychiatry as well as other trainees on the course.

A few months after commencing the training I was appointed the course representative of the “student staff liaison committee”. I felt it was important to organise processes of competent advice that would benefit all trainees on the program. During the first meeting, I advocated the use of regular “peer supervision” meetings. I felt that as trainees worked in such a diverse range of fields, we could all benefit from shared experiences and support. Peer supervision commenced at the start of the second year and proved a useful way to help organise, clarify and access relevant consultation and advice. For my leadership and guidance skills in my role as a course representative I have been awarded a programme representative of the year award (refer to practice log).

Rather than working in isolation, I continually sought the consultation and advice of experts during all aspects of this portfolio and I believe that it has benefitted from these collaborations. Things were often reviewed or discussed with the relevant experts or team. Examples of this are provided by the behaviour change competency, during which I shadowed a team of health trainers before commencing work with clients and with the planning of my research, during which I conducted a “Patient Involvement” group prior to conducting data collection.

1.2d Develop and enhance oneself as a professional applied psychologist.

I was aware of the importance of continuously developing and enhancing myself as a professional psychologist and feel that this occurred organically throughout the training. I joined the Division of Health Psychology and kept abreast of developments in Health Psychology to ensure that I applied the most up to date and relevant findings in my practice. I also became a member of the University’s Research Focus Group, to enhance and develop my writing skills and seek opportunities and collaborations for potential publications. I have regularly attended relevant Health Psychology conferences and have presented the findings from my research at conferences, augmenting my professional skill set. I continually sourced and utilised various sources to further advance and enrich my practice such as: *Applying Psychology to Health* (Banyard, 1996), *The Health Psychology Reader* (Marks, 2002), *The development of professional Health Psychology: European Federation of Professional Psychologists’ Association (EFPPA)* (Marks et al., 1998) and Michie and

Abraham's (2004) Health Psychology in Practice. As well as Susan Michie's Theoretical Domain Framework, which helped inform which model and theory to use for particular interventions, and their most effective method of implementation (Michie et al., 2005).

I set the behaviour change competency within a mental health setting to highlight the overbearing need and potential benefit of implementing Health Psychology with this client group. However, for subsequent competencies I strived to find exciting and challenging opportunities which were often far removed from my area of expertise to ensure that I continually developed and enhanced my professional skills.

1.2e Incorporate best practice into one's own work.

The in-depth CQC Inspection report highlights my attempts to incorporate best practice into my work setting, not just myself but also by supervising others. Although aspects such as smoking cessation do not form part of my role, I was aware of the potential dangers of smoking in patients who were prescribed clozapine as well as their long-term reluctance to attend stop smoking clinics. I, therefore, worked with clients having attained full National Centre for Smoking Cessation and Training (NCSCT) certification as a smoking cessation practitioner. I also completed additional NCSCT qualifications in Face to Face Behavioural Support and the NCSCT Mental Health Specialty module, to support clients that I had already established a therapeutic relationship with, thereby enhancing their well-being and the efficacy of their treatment.

The more I developed and progressed as a trainee Health Psychologist, the more I was able to incorporate more advanced techniques and methods. During my professional development, I was increasingly able to utilise these skills to ensure best practice. I was also able to disseminate the knowledge that I had gained while supervising others to ensure that best practice was maintained throughout my work place. Evidence of this is provided in the CQC inspection report (please refer to practice log).

Unit 1.3 Provide psychological advice and guidance to others.

1.3a Assess the opportunities, need and context for giving psychological advice.

I have had numerous opportunities to provide psychological advice and guidance to others. The organisation that I worked at is a provider of specialist residential and supported accommodation in London. There are several forms of resources, all of which are specifically designed for adults with complex mental health needs. The organisation offers 24-hour support provided from a large pool of multi-disciplined staff including Mental Health Nurses, General Nurses, Psychologists, Social Workers, and Health and Social Care trained staff. Back up is provided from the Local

Community Mental Health Teams (CMHTs), working closely with Forensic Consultant Psychiatrists, Community Psychiatric Nurses and Forensic Social Workers.

The resources can admit patients who may be subject to conditions of section 37/41 of the Mental Health Act 1983 or individuals who are subject to conditions by the Ministry of Justice. Working within this role provided continuous opportunities need and context for providing psychological advice to others both in multi-disciplinary team meetings and during one-to-one sessions with clients.

1.3b Provide psychological advice.

Throughout my professional practice, I remained dedicated to developing a therapeutic relationship with patients based on trust, empathy and understanding as a precursor to providing psychological advice. I regularly undertook literature reviews on relevant areas to ensure that the advice provided was up-to-date and evidence based. A few months after commencing the training I was appointed the Student representative on the course, and within this capacity, I frequently provided advice to peers. I was asked to conduct talks on two induction sessions to prepare trainees for the rigours of the course while providing tips and input. As I progressed through the training, I was increasingly contacted by peers and new trainees to provide advice and input on their work.

1.3c Evaluate advice given.

I utilised a number of methods to evaluate my performance and adapt the content of my advice accordingly. This included feedback forms from the various competencies and advice and input provided from clients, tutors, programme directors, colleagues, trainers, peers and most relevantly, both my academic and workplace supervisors. I believe that I developed a good rapport with all the professionals that I worked with and particularly with my academic supervisor. I was able to work collaboratively, but also responded well to feedback and constructive criticism in a reflective manner.

In my role as Programme Representative I was awarded two accolades a “Lead Student Representative of the Year” award and the Department of Arts and Social Sciences overall “Programme Representative of the Year” award (Please refer to Practice Log).

Unit 1.4 Provide feedback to clients.

1.4a Evaluate feedback needs of clients.

Throughout the training, I had unique opportunities to evaluate the feedback needs of a diverse range of clients. In my professional practice, I provided feedback to a range of individuals including service users, their key workers and family members as well as all the professionals involved in their case such as psychiatrists, social

workers and Community Psychiatric Nurses as well as the board of directors of my organisation in monthly meetings. I evaluated and tailored the feedback according to the requirements and needs of each specific group of clients, and thus the feedback provided to clients can take a variety of forms. This can include verbal one to one sessions, group presentations, or specifically tailored reports. An example of this is provided by the referral feedback that I provide for clients following a referral assessment. The detailed referral feedback report that I provided to the referring agency (Refer to Practice Log) is very different to the funding report that I provide the local authority's funding panel. It also varies considerably from the verbal feedback that I would provide to the client to inform them if their placement request had been accepted, and from the verbal feedback that I would provide to professionals at service users' ward rounds.

1.4b Prepare and structure feedback.

I had several opportunities to prepare and structure feedback throughout the training. I carried out an annual business plan for the unit which incorporates a swot analysis, quality assurance monitoring and a service review process. A triangulation of the results provided me with a systemised structure to prepare and feedback at the annual directors meeting. During this meeting, feedback is reviewed; directors ask questions, provide input and contributions are welcomed. Goals for the following year's business plan are then considered. My role as the supervisor of the staff team was another frequent opportunity to prepare and structure feedback for various professionals.

1.4c Select methods of communicating feedback.

Working with individuals with severe and enduring conditions which have effected their cognitive functioning to varying degrees ensured that I remained mindful of selecting the most effective method of communicating feedback depending on the particular circumstances and client. I have also presented my thesis at the doctoral conference at City, University of London and findings from the research thesis were presented at the BPS Division of Health Psychology conference in September 2017.

1.4d Present feedback to clients.

During the training, I became increasingly comfortable with presenting feedback to clients in various formats and circumstances. Feedback for staff supervisions and appraisals included both verbal face-to-face feedback and a written report. Feedback for other professionals would involve a verbal assessment during a ward round or professionals meeting and a written report, whereas feedback for directors involved PowerPoint presentations accompanied by a detailed business plan for the following year. I frequently assessed and evaluated my feedback and was able to expand upon my communication skills, reflective listening and Socratic questioning. I looked to ensure concordance with the aims, requirements and needs of the client. While completing the Consultancy competence, clients were asked to carry out a variety of feedback forms. I also designed a pre and post programme questionnaire to evaluate the Consultancy. I subsequently presented this feedback during the final evaluation session with the primary client, which proved to be a useful method of highlighting the success of the programme.

Conclusion.

The training has afforded me with the skills to develop and enhance myself as a professional applied psychologist. I felt that there was an element of uncertainty regarding the use of Health Psychology within a mental health project. Throughout my training, I have developed a clear expertise in applying Health Psychology in mental health settings, but I have also developed my skills further by working with other populations. For example, designing and delivering interventions to the general public who wanted to quit smoking, delivering teaching and training to MSc Health Psychology students and conducting training to other healthcare professionals. This has ensured that although there has been a main focus in my training, there has also been considerable variety. The training has highlighted the scope of Health Psychology to be applied within a diverse range of settings. I feel extremely passionately about the numerous benefits of its real-world applications, expanding the boundaries of its implementation and the positive role that Health Psychology can play within mental health populations.

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CORE UNIT 3
DHP 063

CONSULTANCY COMPETENCY
CASE STUDY

Introduction

This case study will provide an account of the experience ensuing from being appointed as an external consultant by the London Hypnotherapy Studio, to deliver the particular task of providing Smoking Cessation support to their clients. It will chronicle the request, negotiation, development, review, monitoring and evaluation of the consultancy contract utilising the relevant theoretical frameworks.

Background

The London Hypnotherapy Studio is a well-established, professional hypnotherapy service, which provides successful and safe treatment for a wide range of purposes. These include:

- Anxiety
- Assertiveness
- Chronic pain
- Confidence
- Depression
- Phobias
- Procrastination
- Public speaking
- Relationships
- Self-esteem and maximising achievement & potential
- Sleep problems
- Side effects of medical treatments

- Stopping smoking
- Stress
- Unwanted habits
- Weight loss

Recent research suggests that hypnotherapy is becoming an increasingly popular therapy, used for a variety of purposes such as smoking cessation. Some of the reasons for this increase in popularity include, the absence of side effects and the enhancement of the feeling of self-control by simultaneously utilising many motivational dimensions specific to an individual (Bonshtein, Shaar, & Golan, 2005).

Hypnotherapy is well-established as a therapeutic tool, utilised by medical professional groupings in a variety of countries for many years. Research suggests that it is an effective and powerful tool for changing patterns of behaviour when utilised as an adjunct to other therapies, including Cognitive Behavioural Therapy (CBT) (Kirsch & Lynn, 1995).

3.1 Assessment of the request for consultancy.

Identification of the client.

In December 2014, it was brought to my attention by the founder of the London Hypnotherapy Studio (LHS), that the organization was facing adversity in meeting client demand for smoking cessation appointments. The organisation anticipated that it would struggle to meet the expected increase in new customers that traditionally followed the New Year Period, while maintaining sessions with regular long-term

clients. The organisation was, therefore, looking to employ an external consultant to help meet these challenges.

Identify, prioritise and agree to expectations, needs and requirements of the client.

I was invited to attend an initial meeting to provide input and discuss these concepts further. This constituted the first exploratory meeting of the consultancy. It is recommended that this meeting is attended by the person who possesses the problem and requires help (Schein, 1999). During this initial contact, I decided to adopt a multi-dimensional approach to the consulting process, incorporating elements of the Process consultation model, the Expert Model of Consultancy and the Doctor-Patient Model (Cope, 2010). At the meeting, the founder of the organisation explained that the organisation was featured on several promotional websites such as “Groupon” and “Wowcher” following which, there would be an anticipated spike in demand in hypnotherapy sessions. Traditionally, there was also increased demand for smoking cessation therapy just after the New Year. However, although the introductory rates would often prove extremely popular and attracted many new clients, it could potentially lead to dissatisfaction amongst existing customers, who would have to pay considerably more for their hypnotherapy sessions. The founder anecdotally explained that many existing clients would often seek to give up smoking as part of their New Year resolutions, and would thus pursue additional sessions for this, further to their regular hypnotherapy sessions. This would potentially result in twice as many appointment requests from many existing clients as well as the forecasted large increase in new clients. We discussed how, although additional Hypnotherapists had been contracted to deal with the heightened demand, this did not address the fact

that new clients would be able to purchase up to three sessions at a lower rate than existing clients.

Due to the agreement with the promotional websites, the advertised reduce rates could not be offered to existing clients for legal purposes. Therefore, LHS had decided to contract a qualified smoking cessation consultant, so that existing clients could be offered smoking cessation sessions. As I am fully qualified with the National Centre for Smoking Cessation and Training (NCSCT), and experienced in smoking cessation, I was therefore requested during this meeting to fulfil this consultancy capacity within my role as a trainee Health Psychologist.

The requirements of the organisation were:

- 1) To work collaboratively to meet the demand for appointments during the first quarter of the year.
- 2) To provide existing clients who agreed to take part in the programme with a tailored smoking cessation programme.

Several follow-up meetings and telephone conversation took place, in order to gain a more in-depth understanding of the expectations regarding my involvement, to assess whether I could help with the problem and to further explore the needs of the organisation.

Review psychological literature and other information sources.

Prior to this initial meeting, I had spent time scrutinising the consulting process itself. Research has suggested that a clear conceptual and operational visualisation of consultation is required to identify the best suited operational models to facilitate the particular consultation process (Kurpius, Fuqua, & Rozecki, 1993).

“Consultancy” has been defined as the process of consulting, with the objective of delivering sustainable value within a diverse range of client situations (Cope, 2010). Consultants are utilised to find solutions that improve the performance of the organisation. Consultancy involves the process of creating value for organisations by improving performance. This is achieved by providing objective advice and implementing solutions. Literature reviews had revealed that the most significant predictor of an effective consultation outcome was to have an accurate problem description that both the consultant and consultee agree on (Bergan & Tombari, 1976; Fuqua & Gibson, 1980; Kratochwill & Bergan, 1990). I adopted a multi-dimensional approach to the consulting process incorporating elements of the Process consultation model, the Expert Model of Consultancy and the Doctor-Patient Model (Cope, 2010). Schein has suggested that the consultant should always start in process consultation mode. This was utilised during the initial assessment period, which had reflected a spirit of inquiry (Schein, 1990). After the opening stage, the model of the consultancy was very much in line with the Doctor-Patient model. The client was aware of the problems but was unsure of the best way for this to be addressed (Schein, 1999). Following the pre-entry stage this had expanded into the Expert Model. The client was able to communicate the problem accurately, had outlined their objectives, aims and

requirements. Therefore, as consultant, I had to ensure that I had the knowledge, skills and competencies to solve the problems and meet the client's needs (Schein, 1999; Cope, 2010).

Assess the feasibility of the proposed consultancy.

A planning and contracting meeting was scheduled in early January. In line with the multi-dimensional approach to the consulting process, this was arranged to clarify consultee needs and expectations (Kurpius et al., 1993). It was decided that the main challenges that the organisation faced were twofold; Firstly, its lack of capacity to meet the increased demand for appointments from clients during the first three months of the year and secondly, its inability to match the reduced rate for hypno-therapy sessions that was on offer for new clients, to existing clients.

Once the problem was defined, the next important step was to reach agreement on the ownership of the problem (Kurpius et al., 1993). It was agreed that an external consultant providing a course of smoking cessation based on traditional methods would allow the company to offer the sessions at a reduced rate. This was because it would not be hypnotherapy that would be provided. Therefore, to appease existing clients the organisation would offer the service free of charge as a gesture of thanking them for their continued valued custom. Furthermore, it would allow the company to focus its resources on new clients during the first quarter of the year, while still retaining existing clients. It was agreed that the course of smoking cessation would be offered to a maximum of 8 clients and only those that chose to take part would

undergo the sessions. It was agreed that the clients would have to undertake the sessions between the months of January to March 2015. Finally, it was also established that from an organisational viewpoint the company did not view the overall success of the consultancy in terms of the smoking cessation success rates, but rather in terms of the clients completing the smoking cessation programme. Following these initial discussions, I considered the consultancy as feasible and set about developing a contract for the process (refer to Appendix).

3.2 Plan Consultancy

Determine aims, objectives, criteria, theoretical frameworks and scopes of interventions.

During the initial meetings with the organisation regarding the feasibility of the consultancy, the aims and objectives had already been well-established as previously outlined. At the pre-entry stage I utilised the Expert Model. The client was able to communicate the problem accurately, had outlined their objectives, aims and requirements. I utilised the knowledge, skills and competencies to solve the problems and meet the client's needs (Schein, 1999; Cope, 2010).

It was agreed that the client required specific knowledge in the area of smoking cessation. I would be able to provide this in my role as a trainee Health Psychologist, through my qualifications in smoking cessation (Full NCSCT Certification as a Smok-

ing Cessation Practitioner) and my experience of conducting smoking cessation sessions with a varied client group (NCSCT Mental Health Specialist). Therefore, the consultancy model that I ultimately utilised, was the purchase of information or expert model. This provided the theoretical framework for the consultancy, in which I took the role of the expert providing a service to the client (Schein, 1990). This model posits that the client accurately knows what the problem is, the client has accurately communicated the real problem, ensured that the consultant knows what is required and that the client is responsible for any consequences associated with the consultancy.

Produce implementation plans for the consultancy.

Prior to finalising the contract for the consultancy, the consultancy plan and timetable were discussed with the organisation. At this stage it was unclear how many clients would take up the offer of sessions. Thus, it was agreed that it would be difficult to have precise timescale, but rather to develop a timeframe that could be regularly reviewed. A consultancy contract was then drawn up and signed by both parties (refer to Appendix)

3.3 Establish, develop and maintain working relationship with clients.

This consultancy involved planned change through the delivering of an intervention. Experts in the field of consultation have stated that the intervention is to enter into an ongoing system of relationships, developed between or among people, groups or objects, for the purpose of helping them (Argyris, 1970).

I had already established a close relationship with the founder of the London Hypnotherapy Studio prior to commencing the consultancy. My working relationship was via telephone conversations and face-to-face contact in the form of professional meetings. I felt that this allowed for the initial stages of the consultancy to develop well, as communication flowed naturally and expedited the process of developing relationships with others involved, whom I had not worked with previously.

During the consultancy, I developed and maintained a close working relationship with office staff at the two locations where sessions took place. Namely West Hill consulting rooms in Highgate and Earls Court Health & Wellbeing Centre.

Ultimately, the key relationship was with the LHS clients that engaged in the smoking cessation sessions. I attempted to develop a therapeutic relationship based on trust empathy and mutual understanding. I felt that this was a vital part of the therapeutic process and strived to continually monitor and evaluate this relationship, which was in due course measured through feedback forms.

3.4 Conduct Consultancy.

Upon delivering the consultancy proposal, a final meeting was scheduled with the organisation (Refer to Appendix). I was informed that five of the eight clients contacted had decided to take up the offer and had been encouraged to make contact to schedule sessions.

There were numerous criteria taken into consideration while I searched for the intervention that best suited the client group. A fundamental set of principles established for classifying interventions prior to their selection is to determine if the focus is on primary, secondary or tertiary helping (Kurpius et al., 1993). These have been referred to as the stages of prevention. Primary interventions are utilised to decrease the likelihood of the problem reoccurring in the future. Secondary interventions are employed to treat pre-existing problems and shorten their duration. Whereas when problem resolution is unlikely, tertiary interventions are utilised to prevent relapse or to comfort clients (Caplan, 1970).

I opted to utilise the Standard treatment programme for one-to-one smoking cessation support as prescribed by the NHS Centre for Smoking Cessation and Training (NCSCT 2014). Knowledge skills and competencies from NCSCT training were also incorporated while carrying out the treatment programme that is considered the benchmark of quality smoking cessation support (NCSCT 2014).

Sessions took place between January the 12th and March the 27th 2015. The programme consisted of two half hour and four one-hour sessions for each participant. The first session was referred to as the “pre-quit assessment”, during which the client was informed about the treatment programme and various assessments regarding readiness and ability to quit were carried out and a quit date set. The second session was arranged for as close to the quit date as possible. This session mainly involved confirming the readiness and ability to quit, discussing withdrawal symptoms, craving and urges and advice on changing routines. I attempted to arrange sections 3, 4 and 5 at approximately weekly intervals. These sessions were very similar in content whereby I would check on the participant’s progress, discuss difficult situations experienced, as well addressing any potential high-risk situations in the coming week and coping methods. I did this by utilising Motivational Interviewing techniques. Motivational Interviewing has been described as a collaborative, goal-orientated style of communication, with particular attention to the language of change (Miller & Rollnick, 2013). It is geared towards the strengthening of personal motivation for and the commitment to a particular goal. This technique allows the practitioner to elicit and explore the individual’s reasons for change within an atmosphere of acceptance and compassion.

During sessions, I attempted to utilise the four processes of Motivational Interviewing namely engaging, focusing, evoking and planning (Miller & Rollnick, 1991). I ensured that I used counselling skills such as open questioning, affirming, reflective listening and summarising in line with Motivational Interviewing procedures (Stott, Rollnick, Rees, & Pill, 1995). The final session took the form of a four-week follow-up appointment. However, the content of an individual face-to-face session varied greatly as

research has highlighted the importance of interaction with smokers being client led (NCSCT 2015). Therefore, I attempted to ensure the interaction was as client led as possible. Thus, some elements of the sessions were individualised based on the particular client.

3.5 Monitor the Implementation of Consultancy.

As outlined in the consultancy contract, it was established that monitoring of the consultancy would take the form of working party meetings. These meetings were arranged in advance and took place separate to the sessions. Regular meetings with the LHS took place throughout the duration of the treatment programme. I ensured that I reported the progress of the programme and kept the organisation informed of developments. Throughout the implementation of the consultancy I ensured that I adhered to The British Psychological Society & HCPC ethical requirements to uphold the highest standards of professionalism, promoting ethical behaviour, attitudes and judgements (BPS Code of ethics and Conduct, 2009). I ensured that I did not disclose what was discussed in sessions with the organisation, but rather reported overall progress of the programme. I endeavoured to adhere to HCPC Standards of conduct performance and ethics (2007) to make sure that I worked within ethical guidelines. I took the lead in keeping the LHS informed of scheduling issues and missed appointments. When issues arose, I reported this to the organisation to seek resolution. The delivery of the programme was relatively straightforward and issue free. The main challenge I faced involved scheduling issues and required a great deal of flexibility and time management on my part.

A further issue that arose was in relation the venues for the sessions. Participants were offered sessions in Highgate and Earls Court. Although I was aware that there was a charge to arrange sessions at each venue, I was not aware that one of the venues could provide consulting rooms on a half-hour basis whereas the other always charged an hourly rate. I did not factor this in when arranging the first half hour sessions but rectified this during the second round of half hour appointments. I also underestimated the travel time between different venues but factored this into subsequent appointments.

In line with good practice guidelines, additional measures were put in place to monitor the process and outcomes of the consultancy. The client (LHS), was asked to complete an assessment at the end of the programme providing feedback on the whole consultancy process. The response of the feedback was largely positive (Refer to Practice Log). Research has suggested that if a client feels confident it is an indication of the success of the consultancy (Earll & Bath, 2004).

3.6 Evaluate the Impact of the consultancy.

In accordance with the organisations policy, all participants were asked to complete out a variety of feedback forms provided by the LHS, following sessions. I also designed a pre and post programme questionnaire to evaluate the Consultancy. Overall, all clients who took up the offer of smoking cessation completed the programme attending all scheduled appointments. The results of the programme indicated that at the four-week follow-up, four of the five clients had continued to remain abstinent

from cigarettes. Feedback from consumers who undertook the programme had been positive with some indicating that they had felt empowered by the process. Client empowerment has been highlighted as a useful method of evaluating the success of consultancy work (Bath et al., 2004).

Outcomes of the aims and objectives of the consultancy process were monitored in various ways. As outlined the aims of the consultancy were as follows:

- 1) To work collaboratively to reduce the demand for appointments during the first quarter of the year.
- 2) To provide existing clients who agreed to take part with a tailored smoking cessation programme.

The assessment that the primary client (LHS), was asked to complete at the end of the process was designed to assess client satisfaction, feedback from the secondary client group (participants), and whether the consultancy met with the aims and objectives (Cope, 2010). The LHS was asked to comment on both the positive and negative aspects of the consultancy, my conduct during the consultancy, what could have been handled differently etc. This monitored the processes and outcome from the client's point of view. The feedback was predominantly positive (refer to Practice Log). The organisation has indicated that they would like to repeat the consultancy with me the following year, which is an indication of the projects success.

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CONSULTING AGREEMENT

THIS CONSULTING AGREEMENT (the "Agreement") dated this 5th day of January, 2015

BETWEEN:

London Hypnotherapy Studio of 2 Hogarth Road, Earls Court, England SW5 0PT

(the "Client")

- AND -

Faisal Satti of City University London, Northampton Square, London, England EC1V 0HB

(the "Contractor").

BACKGROUND:

- A. The Client is of the opinion that the Contractor has the necessary qualifications, experience and abilities to provide services to the Client.
- B. The Contractor is agreeable to providing such services to the Client on the terms and conditions set out in this Agreement.

IN CONSIDERATION OF the matters described above and of the mutual benefits and obligations set forth in this Agreement, the receipt and sufficiency of which consideration is hereby acknowledged, the Client and the Contractor (individually the "Party" and collectively the "Parties" to this Agreement) agree as follows:

Services Provided

1. The Client hereby agrees to engage the Contractor to provide the Client with services (the "Services") consisting of:

- provide smoking cessation support.
- 2. The Services will also include any other tasks which the Parties may agree on. The Contractor hereby agrees to provide such Services to the Client.

Term of Agreement

- 3. The term of this Agreement (the "Term") will begin on the date of this Agreement and will remain in full force and effect until the completion of the Services, subject to earlier termination as provided in this Agreement. The Term of this Agreement may be extended with the written consent of the Parties.
- 4. In the event that either Party wishes to terminate this Agreement prior to the completion of the Services, that Party will be required to provide 10 days written notice to the other Party.

Performance

- 5. The Parties agree to do everything necessary to ensure that the terms of this Agreement take effect.

Currency

- 6. Except as otherwise provided in this Agreement, all monetary amounts referred to in this Agreement are in GBP.

Compensation

- 7. For the services rendered by the Contractor as required by this Agreement, the Client will provide compensation (the "Compensation") to the Contractor of a fixed amount of **£0.00**.
- 8. The client will be invoiced after the work is complete.
- 9. Invoices submitted by the Contractor to the Client are due within 30 days of receipt.
- 10. The Compensation as stated in this Agreement does not include Value Added Tax. Any Value Added Tax required will be charged to the Client in addition to the Compensation.

11. The Contractor will be responsible for all income tax liabilities and National Insurance or similar contributions relating to the Compensation and the Contractor will indemnify the Client in respect of any such payments required to be made by the Client.

Reimbursement of Expenses

12. The Contractor will be reimbursed from time to time for reasonable and necessary expenses incurred by the Contractor in connection with providing the Services under this Agreement.
13. All expenses must be pre-approved by the Client.

Confidentiality

14. Confidential information (the "Confidential Information") refers to any data or information relating to the business of the Client which would reasonably be considered to be proprietary to the Client including, but not limited to, accounting records, business processes, and client records and that is not generally known in the industry of the Client and where the release of that Confidential Information could reasonably be expected to cause harm to the Client.
15. The Contractor agrees that they will not disclose, divulge, reveal, report or use, for any purpose, any Confidential Information which the Contractor has obtained, except as authorized by the Client or as required by law. The obligations of confidentiality will apply during the term of this Agreement and will survive indefinitely upon termination of this Agreement.
16. All written and oral information and material disclosed or provided by the Client to the Contractor under this Agreement is Confidential Information regardless of whether it was provided before or after the date of this Agreement or how it was provided to the Contractor.

Ownership of Intellectual Property

17. All intellectual property and related material (the "Intellectual Property") that is developed or produced under this Agreement, will be the property of the Contractor. The Client is granted a non-exclusive limited-use license of this Intellectual Property.

18. Title, copyright, intellectual property rights and distribution rights of the Intellectual Property remain exclusively with the Contractor.

Return of Property

19. Upon the expiry or termination of this Agreement, the Contractor will return to the Client any property, documentation, records, or Confidential Information which is the property of the Client.

Capacity/Independent Contractor

20. In providing the Services under this Agreement it is expressly agreed that the Contractor is acting as an independent contractor and not as an employee. The Contractor and the Client acknowledge that this Agreement does not create a partnership or joint venture between them, and is exclusively a contract for service.

Notice

21. All notices, requests, demands or other communications required or permitted by the terms of this Agreement will be given in writing and delivered to the Parties of this Agreement as follows:

- a. London Hypnotherapy Studio
2 Hogarth Road
Earls Court, England, SW5 0PT
- b. Faisal Satti
City University London, Northampton Square
London, England, EC1V 0HB

or to such other address as any Party may from time to time notify the other.

Indemnification

22. Except to the extent paid in settlement from any applicable insurance policies, and to the extent permitted by applicable law, each Party agrees to indemnify and hold harmless the other Party, and its respective directors, stockholders, affiliates, officers, agents, employees, and permitted successors and assigns against any and all claims, losses, damages, liabilities, penalties, punitive damages, expenses, reasonable legal fees and costs of any kind or amount whatsoever, which result from or

arise out of any act or omission of the indemnifying party, its respective directors, stockholders, affiliates, officers, agents, employees, and permitted successors and assigns that occurs in connection with this Agreement. This indemnification will survive the termination of this Agreement.

Additional Clauses

23. Mr Satti has declared that the consultancy will count towards units of accreditation for a professional doctorate in Health Psychology and a corresponding account will be included in his portfolio.
24. All individual clients details anonymised.

Dispute Resolution

25. In the event a dispute arises out of or in connection with this Agreement, the Parties will attempt to resolve the dispute through friendly consultation.
26. If the dispute is not resolved within a reasonable period then any or all outstanding issues may be submitted to mediation in accordance with any statutory rules of mediation. If mediation is unavailable or is not successful in resolving the entire dispute, any outstanding issues will be submitted to final and binding arbitration in accordance with the laws of the Country of England. The arbitrator's award will be final, and judgment may be entered upon it by any court having jurisdiction within the Country of England.

Modification of Agreement

27. Any amendment or modification of this Agreement or additional obligation assumed by either Party in connection with this Agreement will only be binding if evidenced in writing signed by each Party or an authorized representative of each Party.

Time of the Essence

28. Time is of the essence in this Agreement. No extension or variation of this Agreement will operate as a waiver of this provision.

Assignment

29. The Contractor will not voluntarily or by operation of law assign or otherwise transfer its obligations under this Agreement without the prior written consent of the Client.

Entire Agreement

30. It is agreed that there is no representation, warranty, collateral agreement or condition affecting this Agreement except as expressly provided in this Agreement.

Enurement

31. This Agreement will ensure to the benefit of and be binding on the Parties and their respective heirs, executors, administrators and permitted successors and assigns.

Titles/Headings

32. Headings are inserted for the convenience of the Parties only and are not to be considered when interpreting this Agreement.

Gender

33. Words in the singular mean and include the plural and vice versa. Words in the masculine mean and include the feminine and vice versa.

Governing Law

34. It is the intention of the Parties to this Agreement that this Agreement and the performance under this Agreement, and all suits and special proceedings under this Agreement, be construed in accordance with and governed, to the exclusion of the law of any other forum, by the laws of the Country of England, without regard to the jurisdiction in which any action or special proceeding may be instituted.

Severability

35. In the event that any of the provisions of this Agreement are held to be invalid or unenforceable in whole or in part, all other provisions will nevertheless continue to be valid and enforceable with the invalid or unenforceable parts severed from the remainder of this Agreement.

Waiver

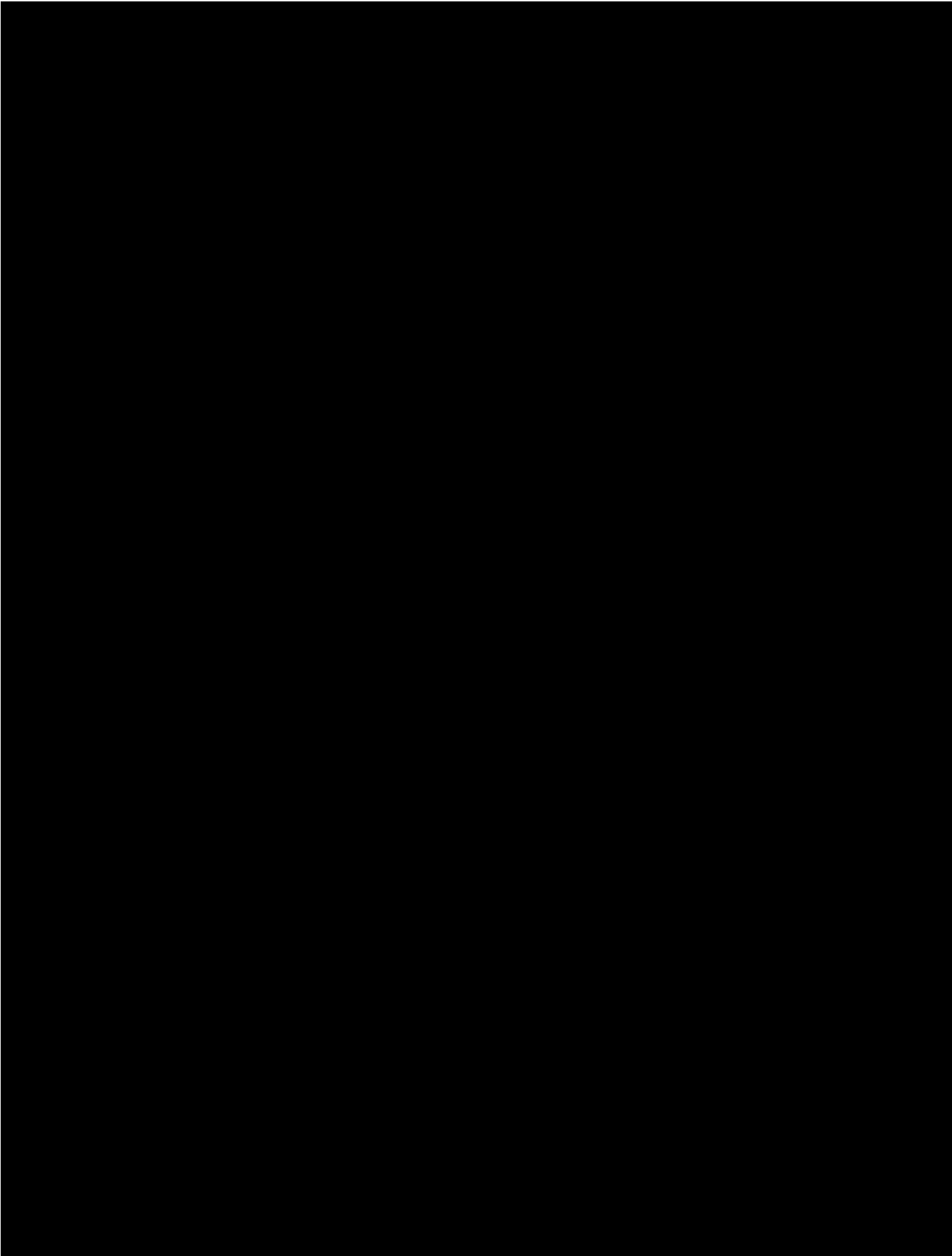
36. The waiver by either Party of a breach, default, delay or omission of any of the provisions of this Agreement by the other Party will not be construed as a waiver of any subsequent breach of the same or other provisions.

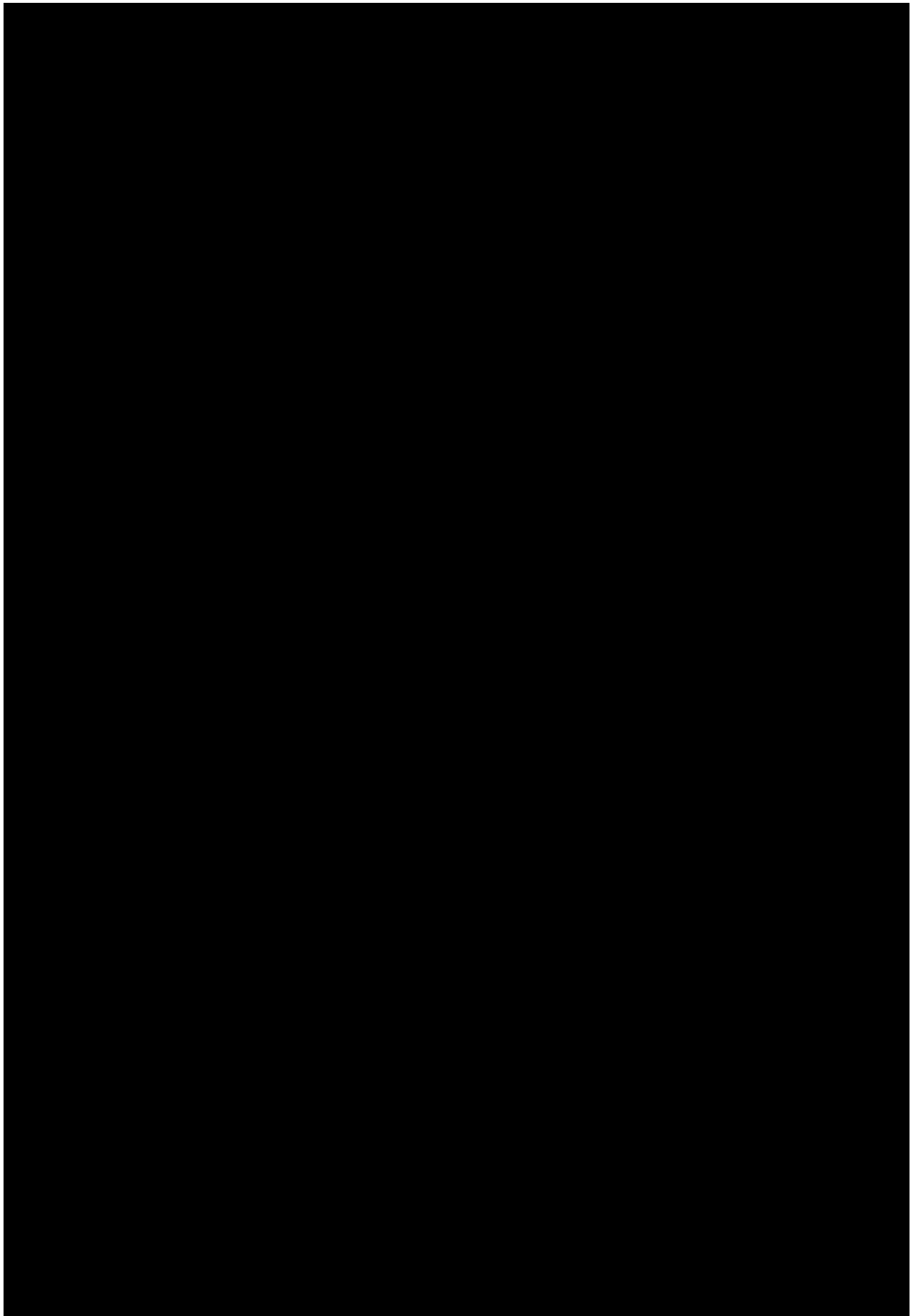
IN WITNESS WHEREOF the Parties have duly affixed their signatures under hand and seal on this 5th day of January, 2015.

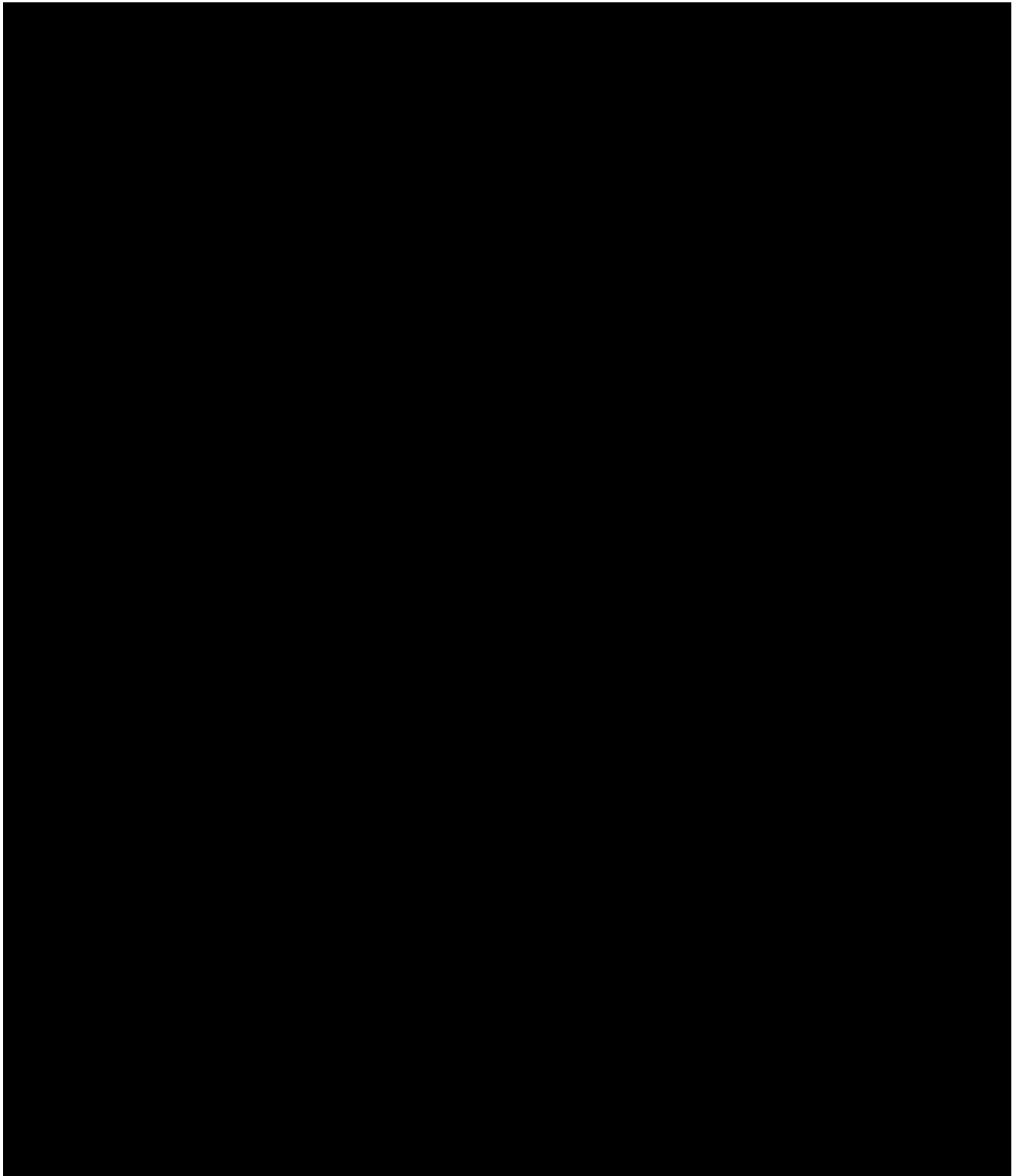
London Hypnotherapy Studio (Client)

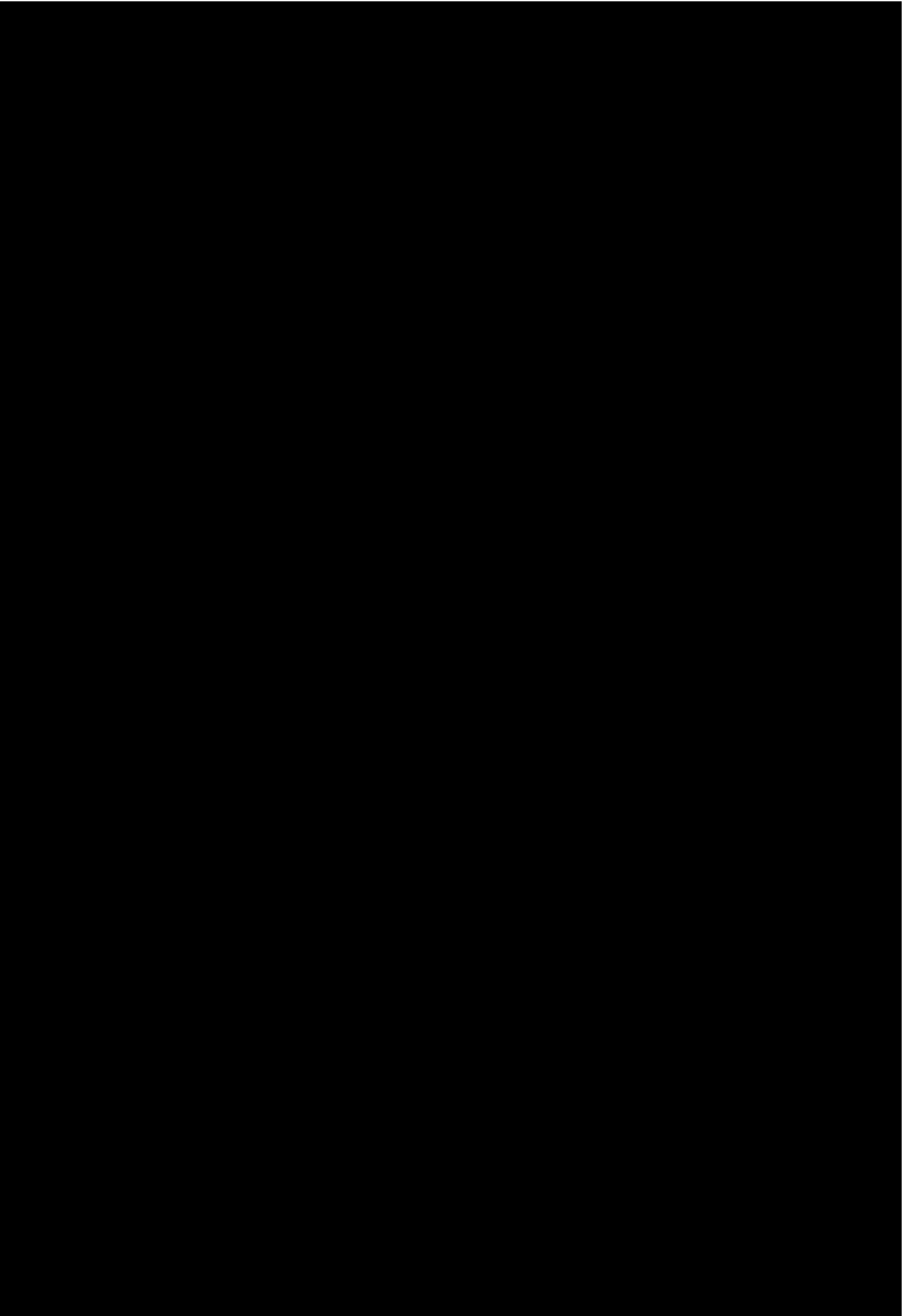
Per: _____
(SEAL)

Faisal Satti (Contractor)









CORE UNIT 4 (DHP 065)

TEACHING & TRAINING COMPETENCE

CASE STUDY A

Behaviour Change, Communication skills and
Healthy Eating Workshops in mental health care
settings

Introduction

This case study will provide an account of my experience of designing and running, a series of workshops designed for mental health care professionals. The training workshops took place at a variety of registered mental health wards and residential services operating under the umbrella of the Prudential Independent Hospitals (PIH) UK Ltd in the North London area. The organisation employs a multi-disciplinary staff team including Registered Mental Health Nurses, Social Workers, Nurses, Occupational Therapists and Consultant Psychiatrists all of whom took part in the training.

4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills & practices.

In December 2014, in my role as a trainee Health Psychologist within the PIH service, I had designed and implemented a behaviour change intervention for service users regarding healthy eating. I gained invaluable insight into issues surrounding healthy eating within mental health settings. This was disseminated within the organisation and my supervisor was eager for me to share the knowledge that I had gained from studying behavioural change within Health Psychology with the rest of the staff team.

4.1 Assess training needs.

Hauer and Quill (2011), recommend a comprehensive needs assessment to assess training needs. In line with this advice, I met with my workplace supervisor - a director at the organisation, to conduct a needs assessment of the required training programme. During the preparation for the behaviour change competency, it became apparent that a great deal of research has highlighted the link between individuals treated with anti-psychotic medication and raised obesity levels (Oliver, Lubman, & Fraser, 2007). PIH is registered to provide support for adults with mental health needs, specialising in individuals with complex severe and enduring mental health issues. It was identified that the organisation attempts to optimise the mental health and physical well-being of patients. A major challenge to the physical health of service users is excessive body weight. This is due to the fact currently the foremost treatment of schizophrenia is anti-psychotic medication, yet a main side effect of anti-psychotic medication is weight gain (Allison et al., 2009) and associated excessive weight gain is purported to expose those taking anti-psychotic medication to serious health risks (Acil, Dogan, & Dogan, 2008).

It was agreed that raising awareness of the benefits of healthy eating, focusing specifically on aiding service users within a mental health setting, would be of great use to staff members within the organisation. We went on to discuss learning objectives as recommended by Heron (1999). It was felt that equipping employees with the required skills, knowledge and confidence to initiate discussions and create support plans for service users relating to healthy eating within a mental health setting would be key. This correlates with the taxonomy of learning objectives (Bloom, Engelhart, Furst, Hill, & Krathwohl, 1956). Three realms of educational activity were identified

by Bloom et al. (1956). Namely; Cognitive - relating to mental skills (knowledge), Affective - relating to growth, emotional areas, or feelings (attitude) and Psychomotor- relating to manual and physical tasks (skills). However, Bloom's taxonomy had faced criticisms in that it did not contain a systematic rationale of construction and was therefore not a fully structured taxonomy (Morshead, 1965). This was subsequently addressed, and the taxonomy was revised to reflect a more active form of thinking (Anderson, Krathwohl & Bloom, 2001). This training would attempt to affect the cognitive and affective domains with trainees acquiring applied knowledge of healthy eating, with attitudes towards unhealthy eating being targeted.

Once the needs assessment and learning objectives of the training workshops was established my supervisor encouraged me to design and structure the training programme for implementation in the summer of 2015.

4.1b Identify training programme structures and content.

While tailoring the programme structure and content, I attempted to ensure that the teaching methods effectively met the learning outcomes (Race & Brown, 2004). I designed the training based on my existing knowledge and experience of applying Health Psychology principles within a mental health setting and spent several weeks adapting the interventions developed as part of the behaviour change competency. While designing the training, I discussed source material with work colleagues and my workplace supervisor. It soon became apparent that while providing staff members with information surrounding healthy eating was essential, another paramount

requirement of the training, would be illustrating how they could raise and discuss these issues with service users.

Service users within mental health settings often have little or no insight into their illness. They often do not consent to treatment having been sectioned and subject to conditions of Section 37/41 of the 1983 Mental Health Act, resulting in a lack of engagement and trust towards health care professionals (Andreasen & Black, 2001). Thus, developing a therapeutic relationship with service users based on trust empathy and mutual understanding is a key component of the of the treatment process. Instructing staff on how to cultivate and practice the required communication skills to develop therapeutic discussions is essential. In my experience, Motivational Interviewing (Miller & Rollnick, 2002) had been an exceedingly useful technique in helping people change health behaviour, particularly in mental health settings. I therefore, decided that the training should include an introduction to the principles and spirit of Motivational Interviewing.

Motivational Interviewing is an evidenced based, client centred style of counselling. It aims to enhance intrinsic motivation to change, by exploring and increasing ambivalence (Miller & Rollnick, 2002). It is a relatively new therapy that has been utilised in addressing a range of behaviours and mental health problems (Miller, Rollnick, & Butler, 2008). Motivational interviewing evolved from the client centred counselling approach developed by Carl Rogers (1951). This is very much in line with the organisations stated outlook and appeared to be an ideal fit for the organisations training programme. I therefore, structured the training programme to contain information on

amalgamating the themes of healthy eating, behaviour change, communication and motivational interviewing into one package.

4.1c Select training methods and approaches.

Further discussion with my workplace supervisor took place in relation to the specifics of the training, including whether it would be voluntary or mandatory, where it would take place, how long it would last for, whether it would be paid or unpaid (for the attendants) and which staff members would take part in the training. I decided to develop a learner profile enabling me to focus on the most effective training methods and approaches for the particular trainee group (Verderber, Jiang, Hughes, & Xiao, 2014). Initially, it was decided that the training would be voluntary and all members of the multi-disciplinary staff team could be invited to take part. However, it was anticipated that the staff members most eager to take part and supplement their existing training would include the support workers, occupational therapists and keyworkers directly involved in behaviour change interventions with service users.

Therefore, I initially decided to utilise a constructivist teaching approach (Hsiu-Mei Huang, 2002) as this allowed me to acknowledge staff members existing knowledge and experience. Specialist research has suggested that it is important to recognise the staff members' knowledge as adults and professionals (Merriam, Caffarella, & Baumgartner, 2007). Trainees would receive further erudition in addition to their pre-existing knowledge and skills, thus supplementing knowledge beyond its original levels. This process has been described as a form of scaffolding (Wood, Bruner, &

Ross, 1976). My aim was to be a facilitator rather than a transmitter of knowledge (Kaufman, 2003).

However, upon further research into learning styles I decided to use a variety of teaching techniques to maximise learning including the didactic and experiential methods of teaching. This was because evidence has suggested that individuals have varying learner styles (Honey & Mumford, 2001). This includes “activists” who learn by taking part in activity; the “reflector” who learn by taking time to reflect on the information provided and those who like to “engage” with what they are learning so that internalisation and transformation can take place (Fry, Ketteridge, & Marshall, 1993).

4.1d Produce training materials.

Professionals who work in mental health frequently have to contend with challenging illnesses, events and extreme circumstances often in seditious situations and environments. This can occasionally lead to a rather insular approach and dismissive stance towards other health care professionals and their input. I, therefore, had to ensure that the training and associated materials were produced in a way that this particular set of trainees would engage with and absorb. I decided to incorporate skill-based activities, such as role plays and work based, real-life group scenario exercises. This promoted learning through activities. It also provided trainees with a chance to reflect and discuss things within a smaller section before presenting their responses to the whole group. This was in line with Honey and Mumford’s (2001)

and Winefield's et al. (2003) emphasis on the importance of allowing individuals time to reflect on their work as well as Jaques (2003) stressing the importance of group discussion as an important tool for developing proactive communications.

4.1e Use appropriate media to deliver training materials.

I designed the training utilising various visual aids such as a PowerPoint presentation, flip chart and handouts. I also used a pack of "food cards" designed by the British Heart Foundation (2013). This provided 56 cards of everyday foods, containing fat, salt and sugar content and designed to improve understanding of healthy eating. This was used to enhance audience engagement and visual comprehension (Race, 2005).

4.2 Deliver such training programmes.

Once the training programme was designed I informed my workplace supervisor to schedule the training. However, this process proved more polemic than anticipated. My supervisor requested that I plan the training on a day suited to myself and contact staff from several of the wards to organise participation. This expanded into an extremely time-consuming process as staff members began providing their availability and asking numerous questions about payments for training attendance. I, therefore, requested the organisation's Events Coordinator to schedule and arrange participants for the training. I provided several dates that I could implement the training on and asked that a minimum of ten trainees would be required for the group exercises

and role-plays to be worthwhile. Once the Events Coordinator took on the task of scheduling and arranging attendance, it allowed me to focus purely on the implementation of the training.

4.2a Implement training methods.

To ensure that I was fully prepared and able to respond appropriately to trainees, I read a number of articles and books on teaching small groups. Research has suggested that the physical environment, including room layout has a significant impact on participation, interaction and learning (Jaques, 2003). On the day of the training I arrived early to ensure that all training materials, the PowerPoint presentation and refreshments were available, I arranged catering and set up the room so that seating was arranged in a semi-circular formation with the screen easily visible to encourage audience participation.

Upon the arrival of trainees, I asked them to sign in, outlined learning outcomes and the agenda for the day and made them feel welcome to ensure that they were equipped and prepared for the day ahead (Race & Brown, 2004). To prompt and encourage discussion, I utilised Socratic questioning (Miller & Rollnick, 2002) to discuss staff member's experiences and to guide the learning process.

4.2b Facilitate learning.

The first training session was attended by 16 individuals including my workplace supervisor and a director at the organisation. To facilitate learning, I utilised didactic, interactive and experiential teaching methods via the PowerPoint presentation, food cards and group reflection exercises respectively. However, the style that I mainly used to deliver the training was that of the democratic facilitator (Exley & Dennick, 2004). This allowed me to work collaboratively with trainees in setting aims, objectives and activities. I began the training by asking questions and then conducted a quiz utilising the food cards, moving on to small group exercises. This led to immediate learning involvement (Silberman, 2004), providing trainees with an opportunity to voice their opinions (Killen, 2007). This resulted in staff members opening up and outlining their experience of behaviour change within mental health settings. I went on to describe reflective listening techniques (Miller & Rollnick, 2002), to illustrate ways to improve communication and engagement levels within mental health settings. While facilitating the training, I endeavoured to check understanding, offer clear instructions and provide positive feedback to the audience to enhance trainee participation in the sessions.

4.3 Plan and implement assessment procedures for such training programmes

4.3a Identify assessment methods

4.3ba Select assessment regimes

4.3c Establish the availability of resources for assessment procedures

4.3d Produce assessment materials

4.3e Ensure fair appreciation of assessment methods

4.3f Produce relevant records of progress and outcomes

The organisation did not want formal assessment for the workshops as it was felt that this might hinder attendance. Therefore, training was not assessed. Instead, I designed a feedback form to evaluate participant ratings (refer to practice log). I gathered feedback from all participants at the end of each training session. I also actively encouraged participants to provide verbal feedback where appropriate and I received verbal feedback from my supervisor. After the initial training, I reflected on these assessments and decided to adapt and modify a new feedback form to take into account learning outcomes through confidence ratings (Winefield et al., 2003).

Unit 4.4 Evaluate such training programmes.

My workplace supervisor and a director of the organisation were both present at the initial training session, following which they stated their pleasure of its content and how relatable and pertinent it was for staff members. They felt that it provided real world context of the benefits of the application of Health Psychology within mental health settings. They requested that I continue to roll out the training and that it would be made mandatory for staff members. This resulted in me carrying out a total of 9 sessions for 137 employees.

4.4a Evaluate training programme outcomes.

I utilised three methods of evaluation throughout the training programme. Evaluation forms completed by trainees, an observers report (please refer to practice log) completed by my workplace supervisor and self-reflection following each training session. Trainees were asked to complete a feedback questionnaire at the end of each session. This involved ten questions in total. Six questions where trainees were required to rate various aspects on a Likert scale and four open-ended questions where they were requested to provide more in-depth responses. This was because the original questionnaire (please refer to practice log) which was all open-ended had a poor response rate.

At the end of each session, I would reflect on the programme and analyse the response of the feedback form. I would take suggestions on board and adapted the training accordingly. This included arranging for warm beverages to be made available, including recipes from various cultural cuisines while specifying religious requirements and repositioning seating in a way to minimise noise from passing trains. On the whole feedback was extremely positive.

4.4b Identify factors contributing to training programme outcomes.

The qualitative comments on the feedback form were instrumental in informing training programme outcomes. Questions included suggested changes and areas of improvement. Several of the respondents mentioned having to go through such a vast

amount of information in the allocated time. On reviewing these comments, I discussed how to better meet the learning outcomes with my workplace supervisor and as result workshop times were extended so that training delivery could be adapted.

4.4c Identify improvements for the design and delivery of training for implementation in future programmes.

I was in the fortunate position to constantly be able to review and adapt the training programme, as I had the opportunity to amend things on eight occasions. I feel that my skills were progressively developing and the training was greatly enhanced with each session, particularly in terms of time-keeping, vocal delivery and confidence.

One of the ways that training could potentially have been improved may have been by providing a handout incorporating the whole training to each participant. As the training involved 142 different slides, work based practicalities prevented me from being able to do so. Also, responses on the feedback form suggested that the training may have benefited from being prolonged into a two-day session. Once again, work based issues around arranging staff cover prevented the organisation from allowing me to do so.

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Appendix

Workplace Supervisor Report

Feedback

WORKPLACE CONTACT REPORT

SECTION A: To be completed by the trainee

| | |
|----------------------------------|--------------|
| Name of Trainee | Faisal Satti |
| Name of Workplace Contact | John Kearns |

Nature of Work and Competence Assessed

Staff Training Workshops
(Teaching and Training competence)
Date of the workshop: 15.06.2015
Time of training: 9.30-16.30 (7 hours)
Attendees: 16 Mental Healthcare Professionals.

SECTION B: To be completed by the Workplace Contact

Views on the Trainee's Performance on above piece of work (write comments below or email a separate report)

I attended the first training workshop that Mr Faisal Satti delivered. The workshop was attended by fifteen other professionals working in mental health. Mr Satti outlined the aims and objectives that he would cover and explained that the workshop would be divided into four sections with scheduled breaks. What immediately struck me was his ability to put everyone at ease ensuring all in attendance were comfortable yet attentive.

The amount of material that Mr Satti covered was vast yet he explained things well. He would discuss theories but would then provide real world examples that other professionals could relate to. The session was extremely interactive with group work. Initially some of the attendees appeared reserved but following a cue card quiz early in the healthy eating section all attendees became more active in discussions.

Mr Satti used a power point presentation but also used frequent activities such as role plays, quizzes, video clips and a cue card games which ensured that the session was fun and diverse. The trainees had the opportunity to ask questions and discuss their experiences.

I was extremely impressed with the standard of the training session particularly as it was the first workshop. The feedback I received from others was also extremely positive. Due to the high standard of this session Mr Satti was requested to roll out the training he had designed to all staff members employed by the company. He was later asked if he could incorporate Recovery Model training into the workshops which was agreed to do. Overall the training was extremely successful and all feedback was positive.

Please return this form to City University by one of the following means:

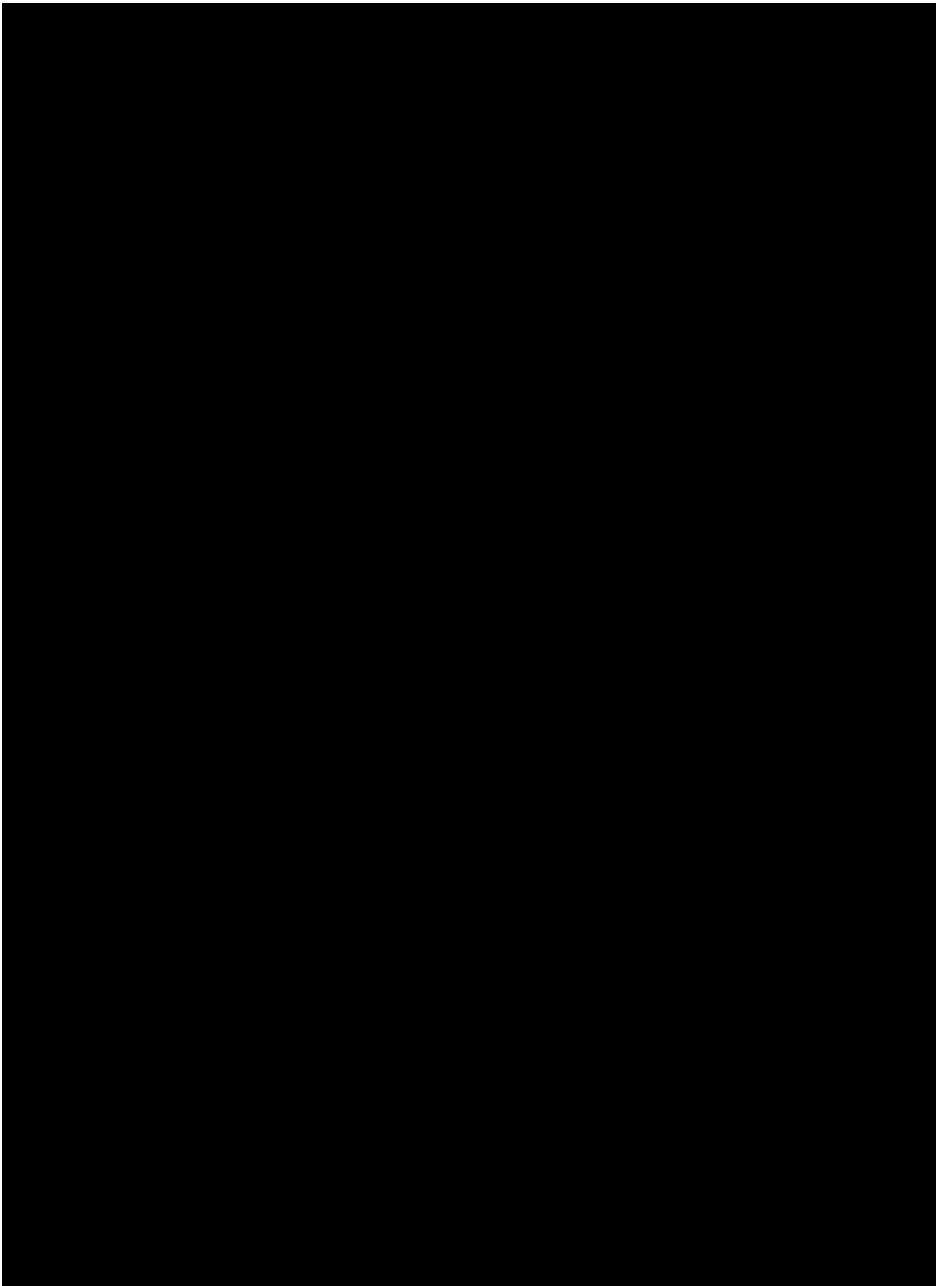
Post: Department of Psychology. City University, Northampton Square, London EC1V 0HB

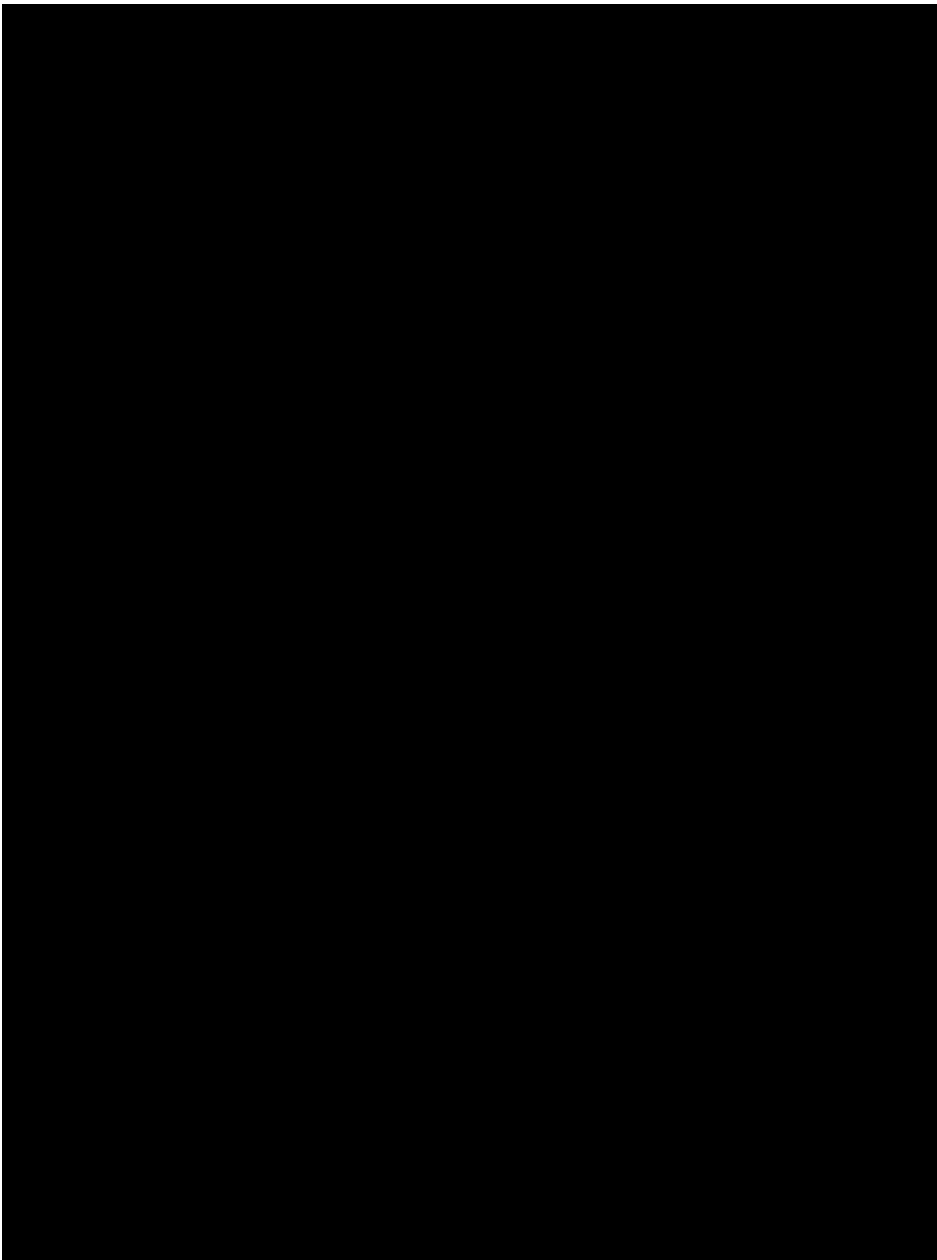
Email: Renata Pires, Email: [REDACTED]

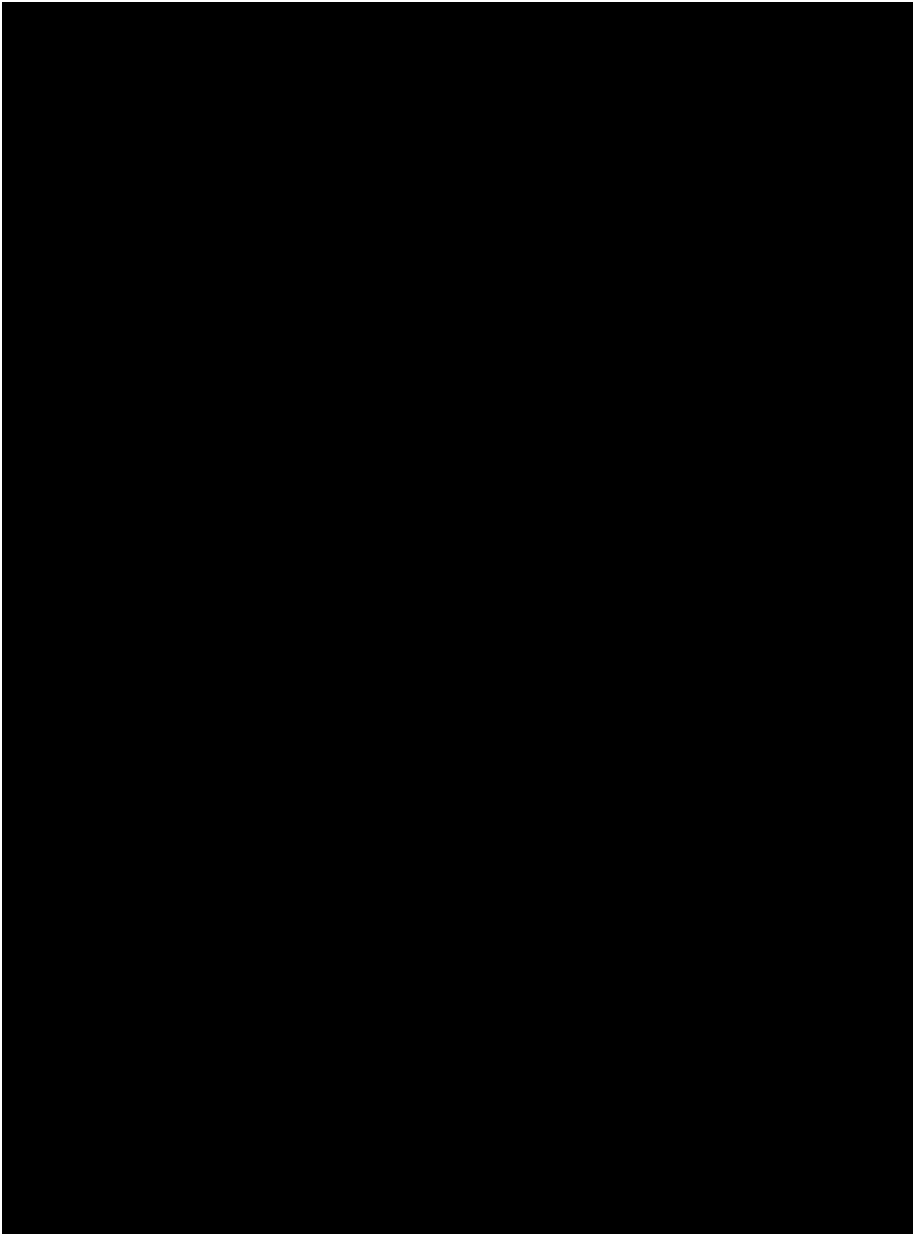
Declaration

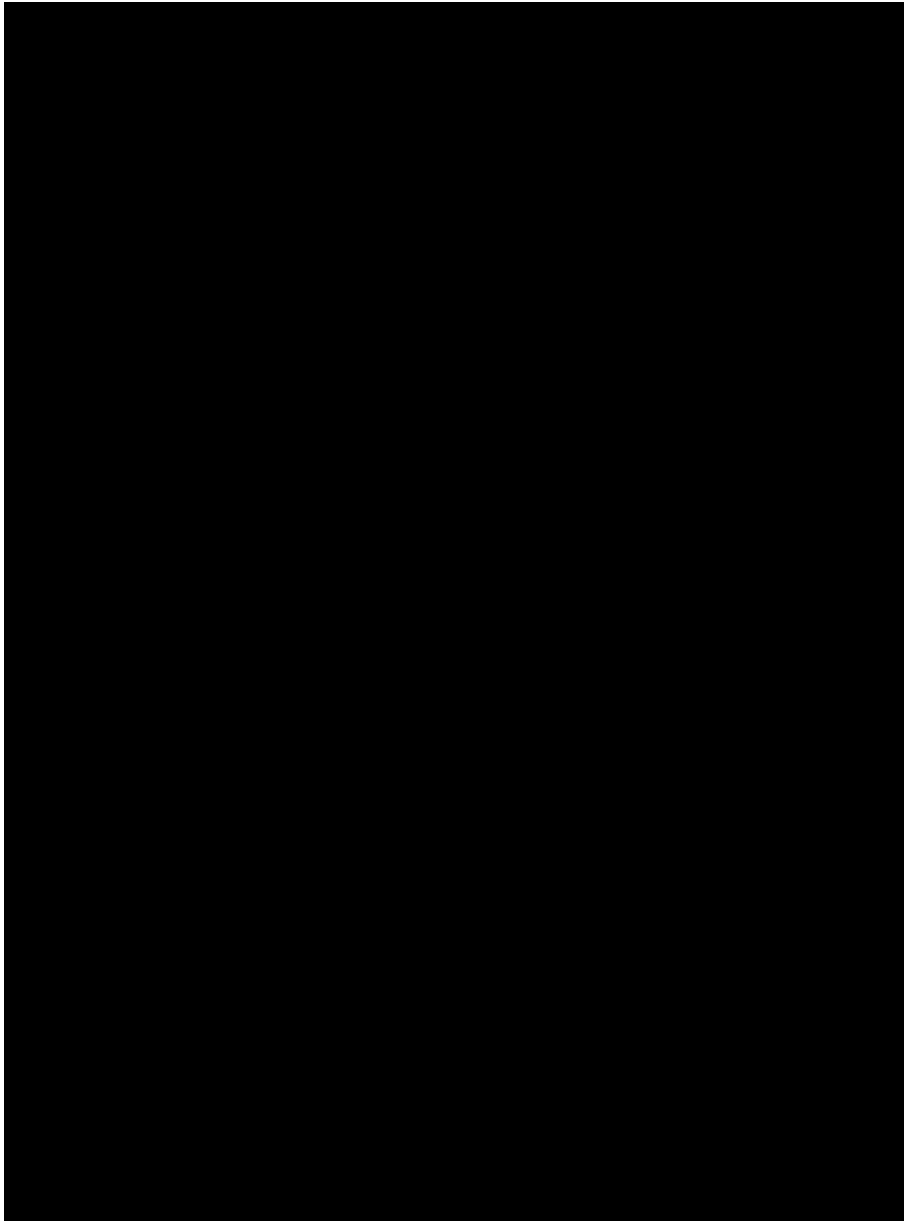
I verify that the above named trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

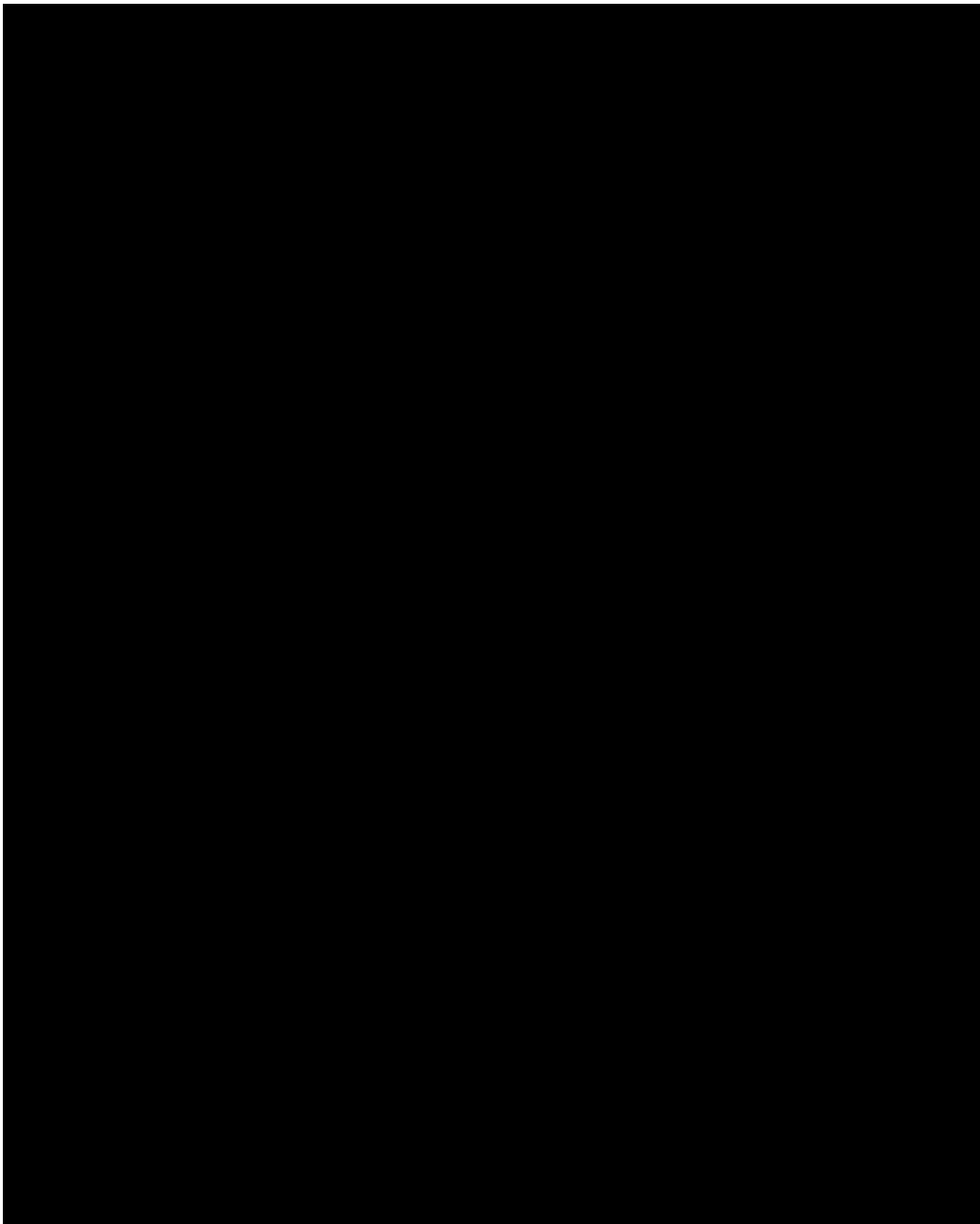
Signature: _____ Date: _____

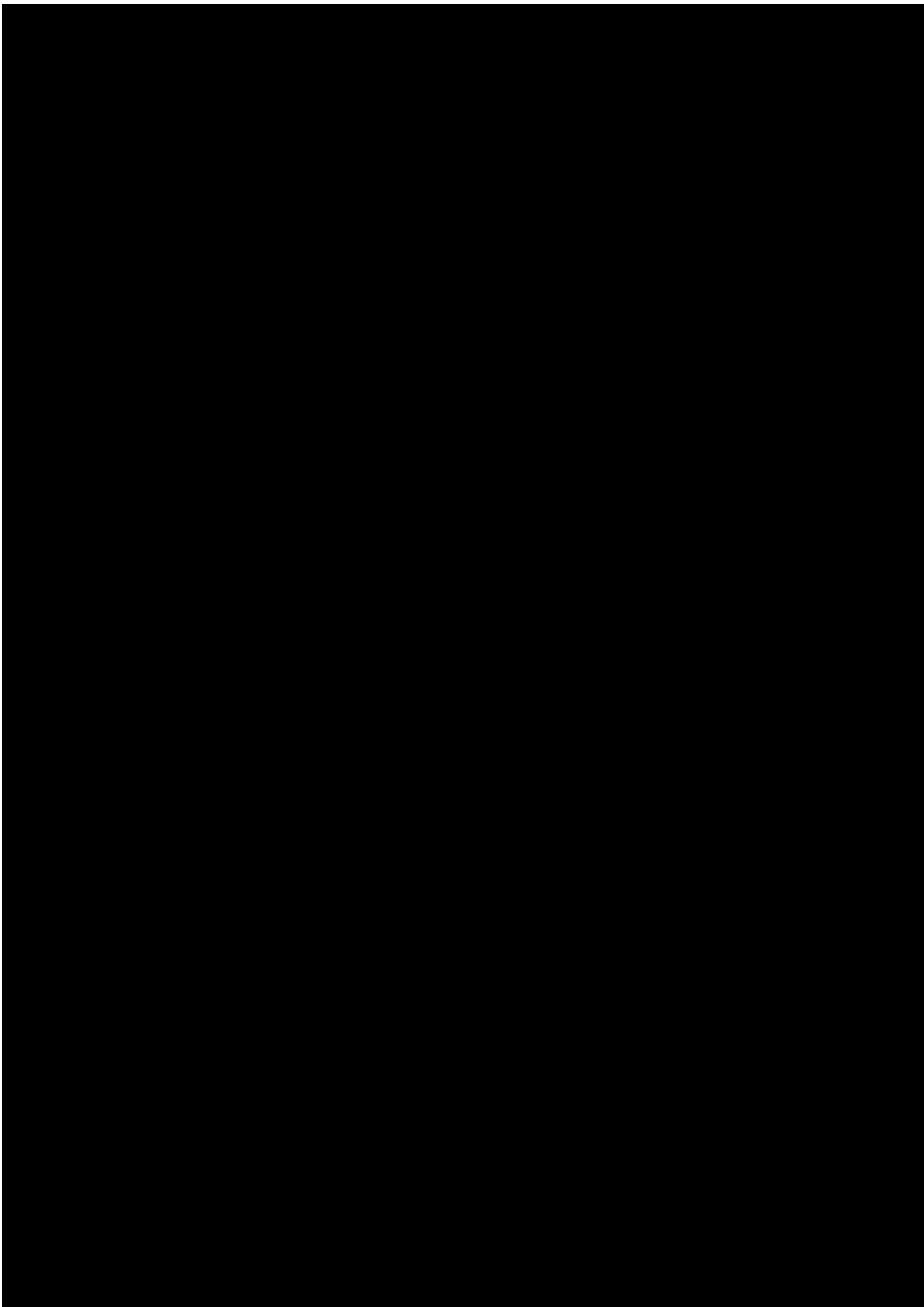


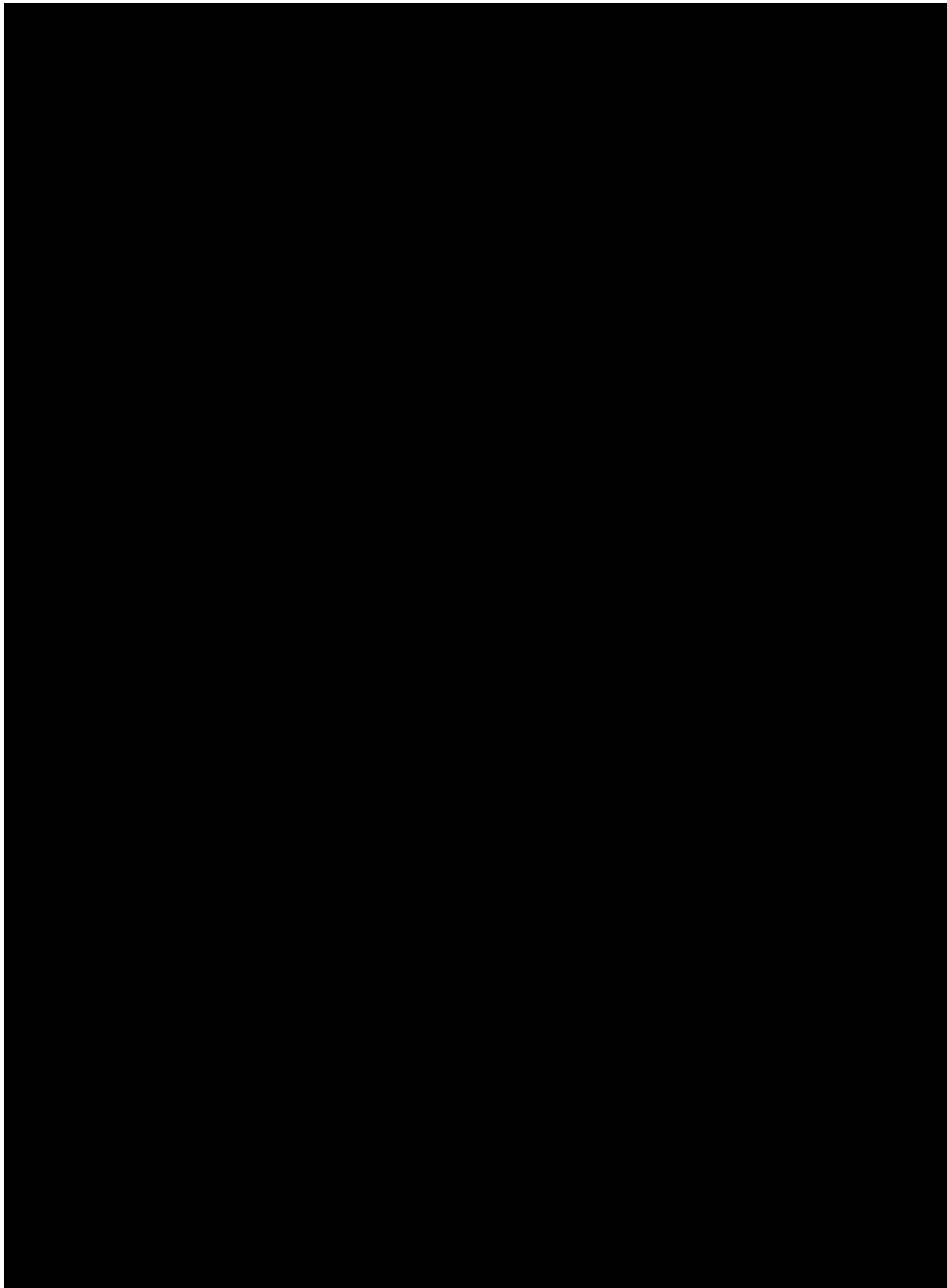


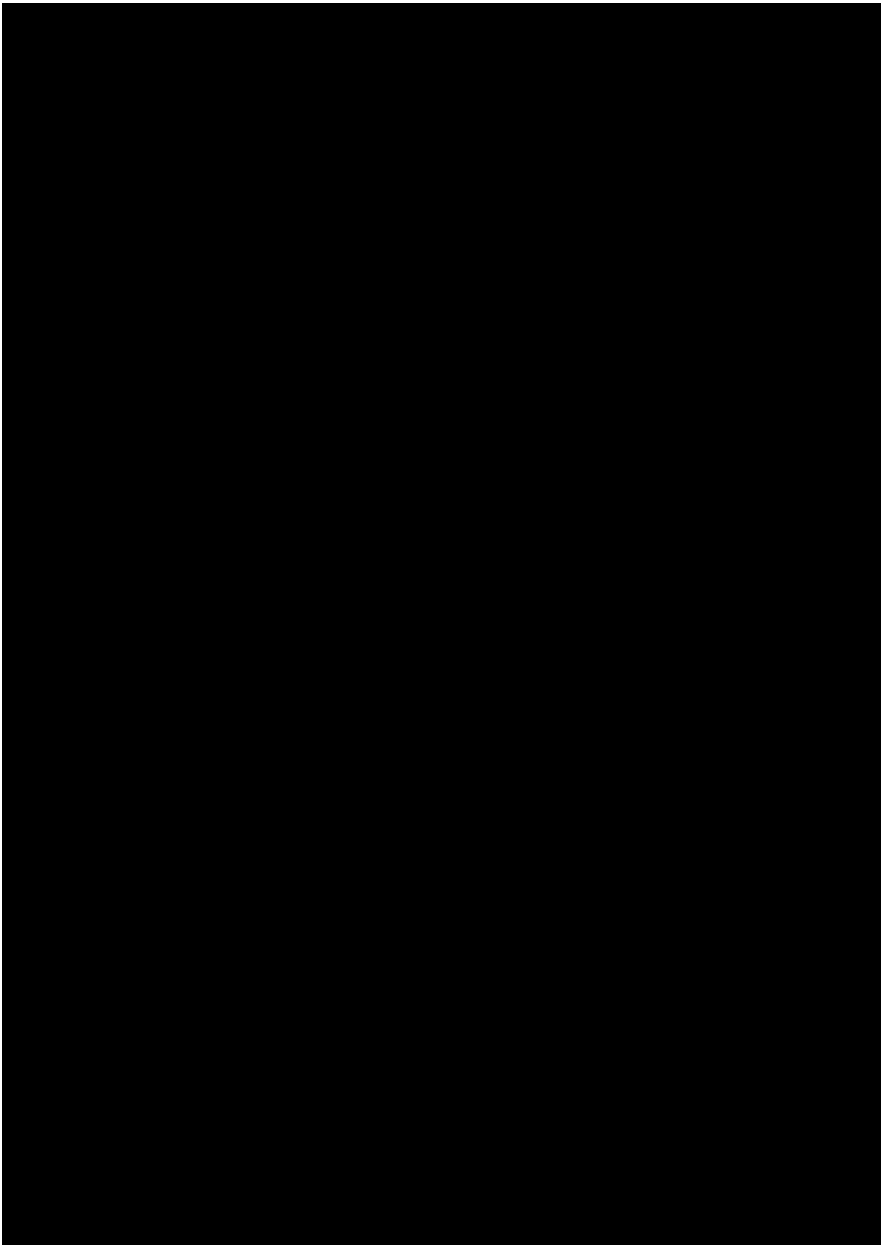


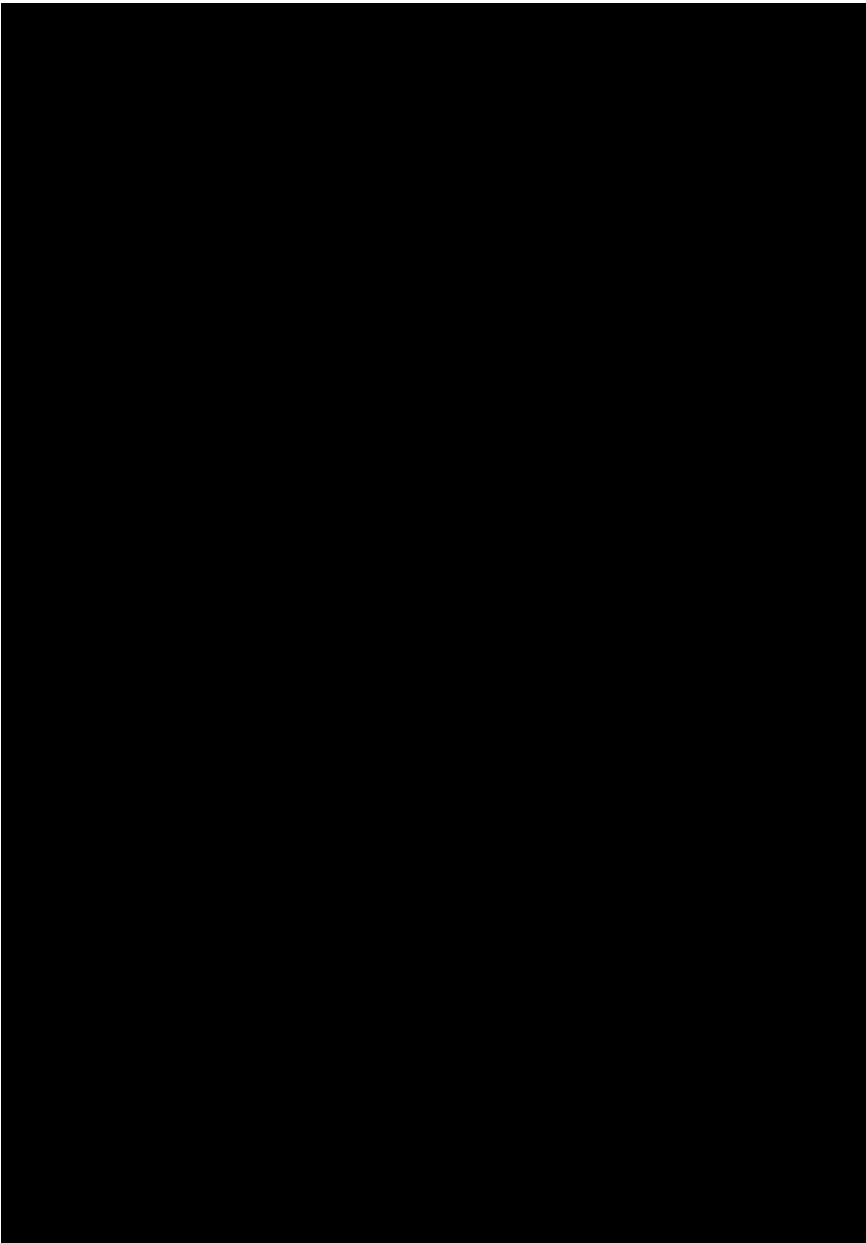


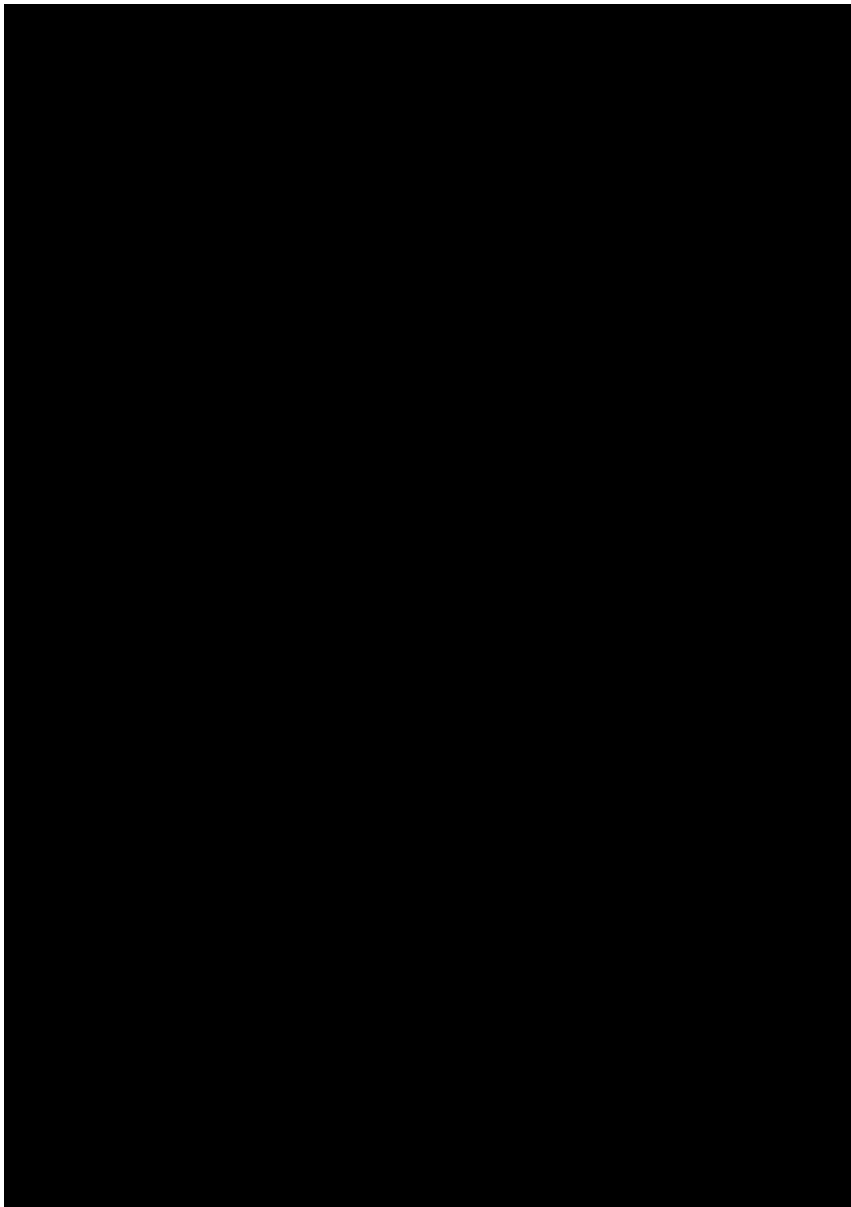












CORE UNIT 4
DHP 064

TEACHING & TRAINING COMPETENCE

CASE STUDY B

MSc Lecture: Social and Psychological Consequences of Alopecia

Introduction

This case study will provide an account of designing and conducting a lecture on the Masters programme at City, University of London. The three hour lecture took place on the 17th of March 2016 and was attended by fourteen MSc Health Psychology students.

4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills & practices.

During a supervision session in November 2014, I discussed the possibility of conducting a lecture on the master's programme at City, University of London with my Academic Supervisor. We deliberated on the training needs of the students and my area of expertise. Potential topics were reviewed, and it was agreed that I would conduct a lecture the following academic year. On June the 22nd 2015, my Supervisor contacted me to ascertain if I would prefer to conduct a lecture on the psychological impact of Alopecia (the area of my systematic review) or health behaviour interventions in mental health settings (the area of my work practice). As I was eager to maximise my lecturing experience, I requested to conduct a lecture on both topics. However, for the purposes of this case study I will expand upon the lecture I delivered on the psychological impact of Alopecia.

The first step when designing a lecture or training is to assess the students training needs (Hauer & Quill, 2011). I therefore, liaised with the Module coordinator to conduct a needs assessment of the required lecture and deliberated on the content of the course programme, the levels of student's knowledge, the content of the module, module aims, objectives and learning outcomes. I also obtained a description of the module, a list of sessions and a session's overview.

At Masters Level (level 7), students are Stage 1 trainee Health Psychologists, taught to use psychological principles to promote changes in people's behaviour and their associated beliefs about health and illness. According to Bloom's updated taxonomy (2001), at this level students should be able to demonstrate synthesis and naturalisation. Furthermore, Heron (1999) recommends setting the learning objectives early and it was agreed that raising awareness of the social and psychological impact of Autoimmune Alopecia, would be of use in exploring concepts of coping with a chronic illness amongst the students. It was therefore decided that for the detail required at Masters Level, it was appropriate for the lecture to comprise of four main learning outcomes, as including more would be beyond the scope of a single three-hour lecture.

While designing the lecture, I was aware of the need for learning outcomes to be effectively addressed through the teaching methods (Brown & Race, 1995). I had conducted a great deal of research on the subject matter having recently completed an extensive systematic review and I had tabulated the research evidence. However, much of this information was written in an academic style and I wanted to ensure that the lecture was dynamic and informative.

Knowing about MSc students' academic backgrounds and topics covered in the module, I was better able to choose the most effective training methods and approaches for the lecture (Verderber, Jiang, Hughes, & Xiao, 2014). Alopecia is not a common skin disorder. Therefore, I ruled out employing a constructivist teaching approach (Huang, 2002), as I could not assume that students would have previous knowledge and experience in this area. For this lecture, I aimed to cover materials that would supplement students' knowledge (Kaufman, 2003), while acknowledging their current experience and expertise (Merriam, Caffarella, & Baumgartner, 2007).

The first draft of the lecture that I designed, was largely based on the research I had recently conducted and contained lots of statistical data. However, my recent experience of conducting training and a lecture on the course had made me aware that there are various learner styles (Honey & Mumford, 2001). Upon further research into learning styles, I decided to utilise assorted teaching techniques to optimise learning. I went on to develop a visual quiz, cue games looking at celebrities and animals with Alopecia, video diaries of patients and various real-life case studies, to promote emotive discussion. This was to stimulate "activist", "reflector" and "engager" learning styles (Fry, Ketteridge, & Marshall, 1993).

4.2 Deliver such training programmes.

I arrived at the lecture room early to ensure there was sufficient time to set up and test material as recommended by Race and Brown (2004). This proved extremely

useful, as I discovered that the fonts used on the headings of the PowerPoint presentation were not available on the lecture room computer. However, I had enough time to rectify this. Seating was arranged in a semi-circular formation, promoting an environment for questions and answers and to encourage discussion (Jaques, 2003).

To facilitate learning, I utilised didactic, interactive and experiential teaching methods via the PowerPoint presentation. After explaining the types of Alopecia, I carried out a celebrity quiz to familiarise students with the various forms of Alopecia, followed by a discussion on animals with Alopecia to draw parallels with humans. This promoted immediate learning involvement (Silberman, 2004). I then moved on to looking at data from Alopecia studies, video diaries of patients, case studies and group reflection exercises providing students with an opportunity to voice their opinions (Killen, 2007). This resulted in students opening up and outlining their thoughts and feelings on the psychological and social impact of chronic illness

From my previous experience in delivering teaching and training, I know it is best to keep my slides simple and talk around them, this also makes the arguments and learning points flow more easily (Winefield, 2004). My slides were not overloaded with text and care was taken not to go below font size 20 (Farrow, 2003).

4.3 Plan and implement assessment procedures for such training programmes.

As the lecture was part of a structured MSc programme, formal procedures for assessment had been established prior to the lecture. Once the needs assessment and learning objectives of the lecture were established my supervisor encouraged me to design the lecture to fit in with the unit structure. As part of the lecture, students were arranged into “teams” and asked to take part in a visual quiz (refer to practice log). This was to provide students with encouragement, feedback and gave them the opportunity to reflect and discuss things within a smaller section, before presenting their responses to the whole group (Honey & Mumford, 2001). As group discussion is considered a key tool in developing proactive communications (Jaques, 2003).

Unit 4.4 Evaluate such training programmes.

An evaluation form (refer to practice log) was designed to assess how successful the lecture had been in meeting the aims and objectives. The evaluation form was provided to all fourteen students who attended. Five questions were made up of a five point Likert scale assessing improvements in knowledge and four open ended questions allowed students to record their views, comments and advice on the lecture. 100% of students strongly agreed with the statement that the training was “well-prepared and presented”. 71% of participants strongly agreed that “the aims and objectives were well set out”. 71% strongly agreed that “the various sections of the lecture made sense to me: I understand their purpose: 92% “felt encouraged to participate and respond to others” and 92% felt “the instructor treated the trainees with respect”. I was extremely pleased with the overwhelmingly positive feedback provided by the students in the open ended questions (refer to appendix). Comments included “clear, good presentation and funny”, “encouraging everyone to take part

with various activities to keep students attention”, “funny and great speaker”. To the question; “What suggestions would you give to improve the instructor’s teaching” one student commented “Nothing, it was a lovely lecture”. However, two respondents suggested that my voice was low at points, while one suggested “slow down a bit on the more technical slides”. Although I checked that everyone could hear me at the start of the lecture, in the future I will endeavour to maintain the volume and tone of my voice consistently and talk louder if competing with external noises. I will also look to improve the pacing of more technical parts of lectures by double checking that everyone has understood things and delivering information at a slower pace.

When preparing the lecture, I felt nervous about the prospect of being asked technical questions, but also excited by the opportunity of developing what I hoped would be an informative but fun lecture, and disseminating some of the findings and knowledge that I had gained during the development of my systematic review on Alopecia. While carrying out the lecture, I felt surprisingly relaxed and comfortable. I felt that I was quickly able to establish a good rapport with the students by involving them in a visual task and engaging in anecdotes and humorous discourse regarding celebrities and animals. I believe that this helped set the tone for the lecture, with everyone engaging well and willing to take part in the activities. I enjoyed designing, planning and delivery the lecture immensely, it strengthened my interest in pedagogy and I subsequently enrolled on a course in academic practice to gain formal qualification as an Associate Fellow of the Higher Education Authority. If I were to deliver the session again, I would ensure that there was more time to discuss the final section where students were encouraged to develop interventions for their fictional client, as some of the suggestions put forward were excellent while others may have

benefitted from more detailed deliberation regarding their planned intervention. My Academic Supervisor also attended the lecture and provided a formal evaluation report (refer to appendix).

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APPENDICES

1. Observers Report
2. Feedback Forms
3. Lecture Slides

Module: Behavioural Medicine, PSM407

Title of the session: Coping with alopecia

Date of the lecture: 17.03.2016

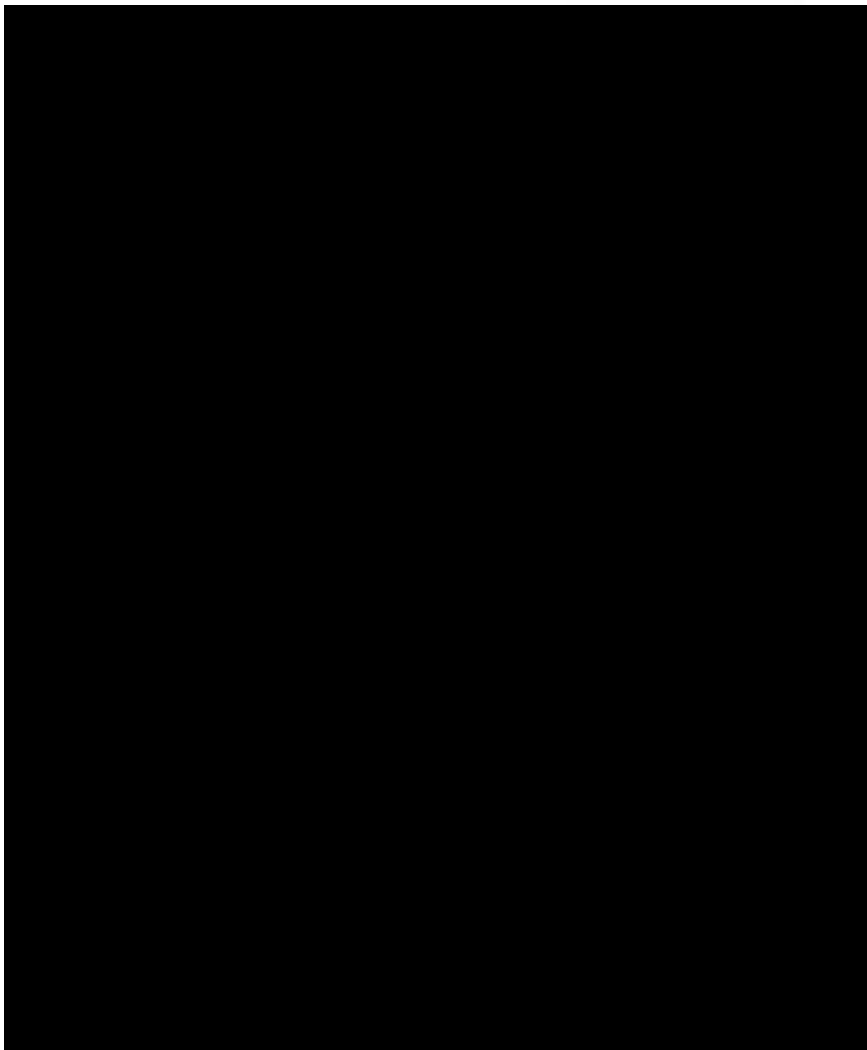
Time of training: 9.00-12.00 (3 hours)

Attendees: 14 MSc health psychology students

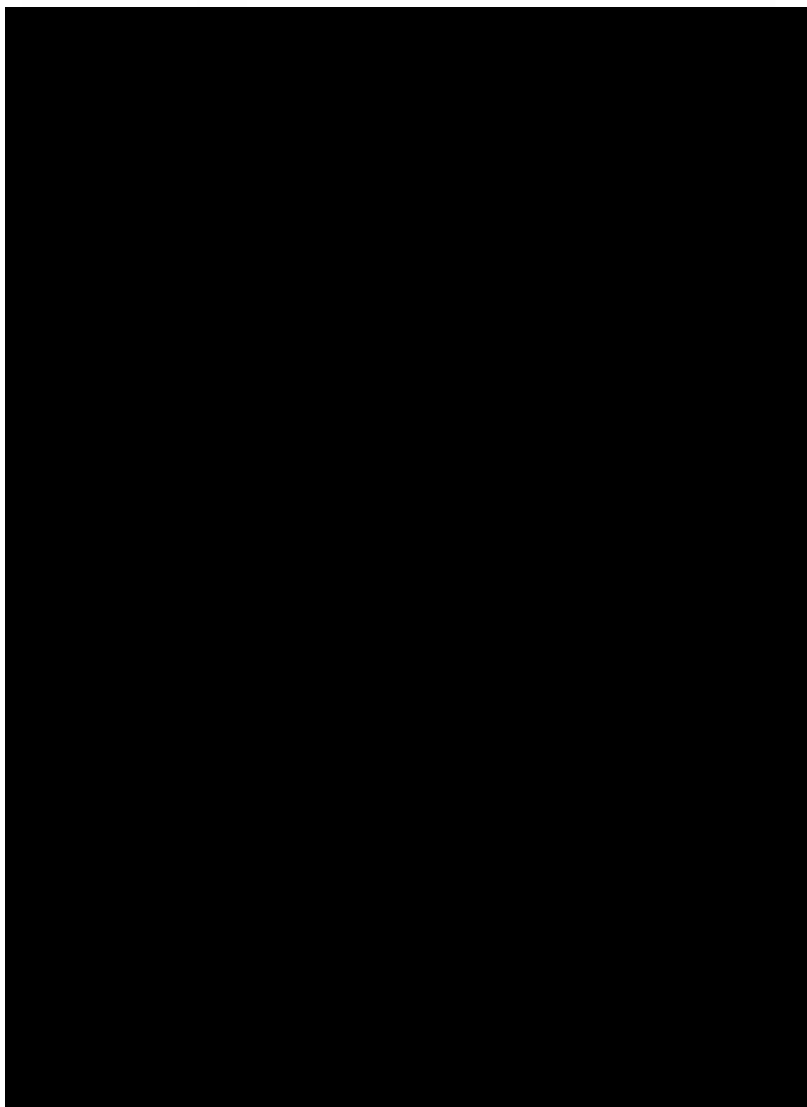
Observer: Dr Angeliki Bogosian

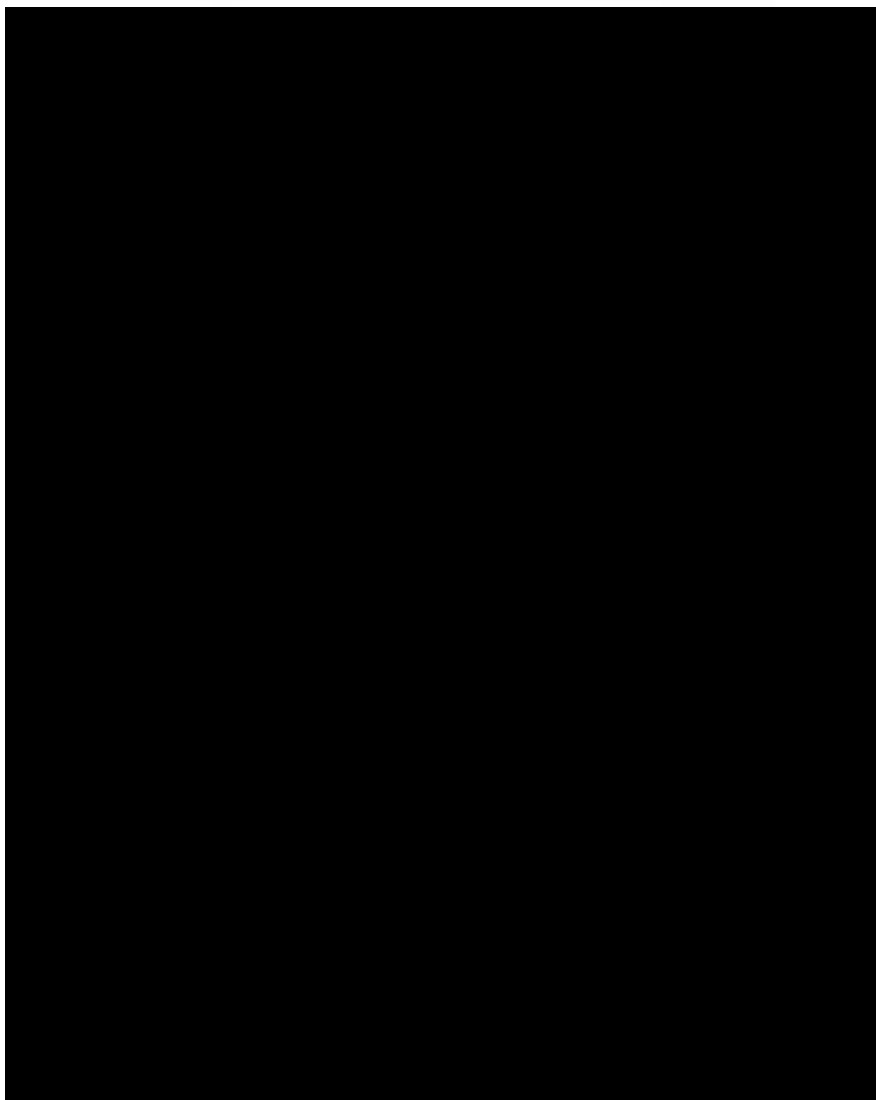
Supervisor's feedback:

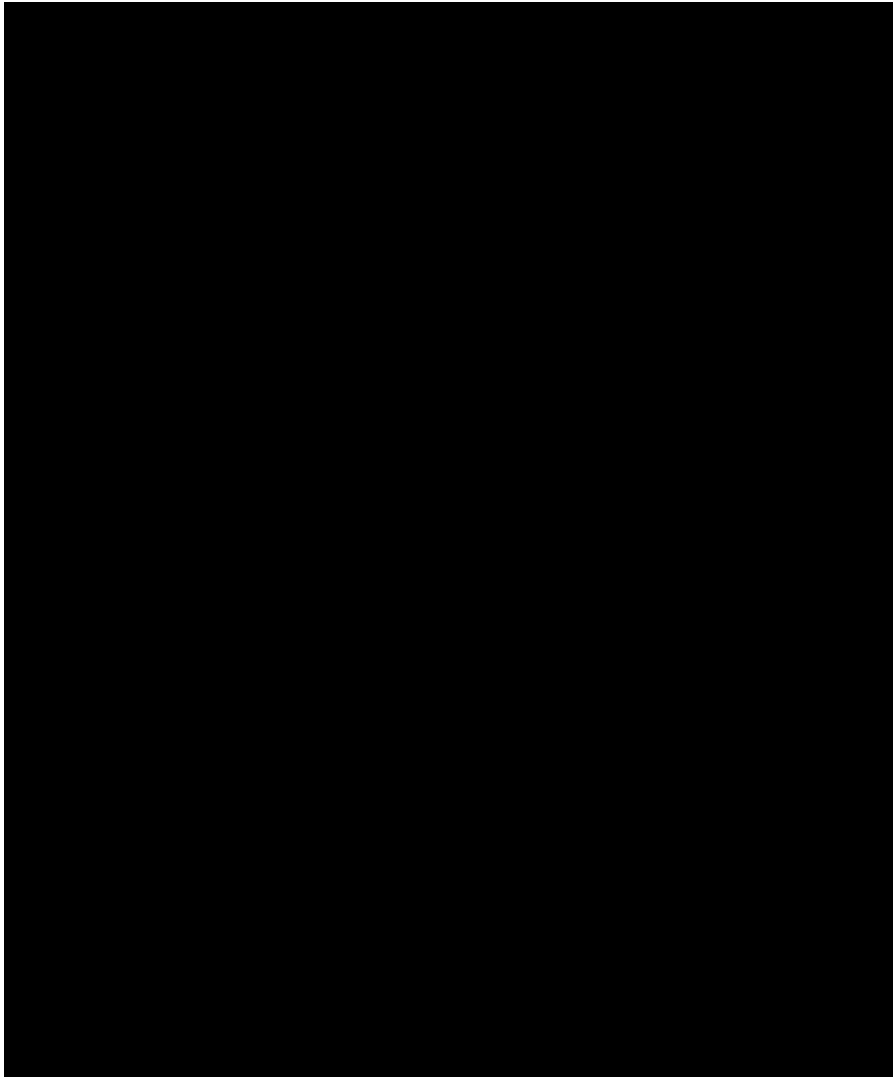
Faisal delivered a very engaging and informative lecture on psychosocial factors associated with alopecia. The session was very interactive, and Faisal was assessing students' understanding regularly. In the beginning, Faisal set clear objectives of the lecture and gave definitions of different types of alopecia, followed by a quiz. The overview of the psychological context in alopecia was concise and accurate. Faisal was able to talk around his slides well, he is clearly very knowledgeable, and he answered students' questions well. His arguments were based on research evidence with references given in the slides. He used examples that draw the attention of the students and made his points clear, e.g. using examples of famous people or animals with alopecia or other everyday examples that made his key points memorable. He was professional and friendly during the session and managed to put everyone at ease. He used a mix of different teaching modalities, e.g. slides, group work, video clips, perspective taking to facilitate learning. Activities he had put in place (e.g. case studies, quizzes etc) proved to be very popular with students. Students got the chance to engage with the material and understand the psychological factors involved in managing alopecia. The slides were very well put together with lots of images that complemented the content nicely. Overall, I was very impressed by the high standards of this lecture. At the Student Staff Liaison Meeting at the end of the year, students commented on how much they liked Faisal's lectures and they were happy to see him again after the lecture he delivered in the previous semester.

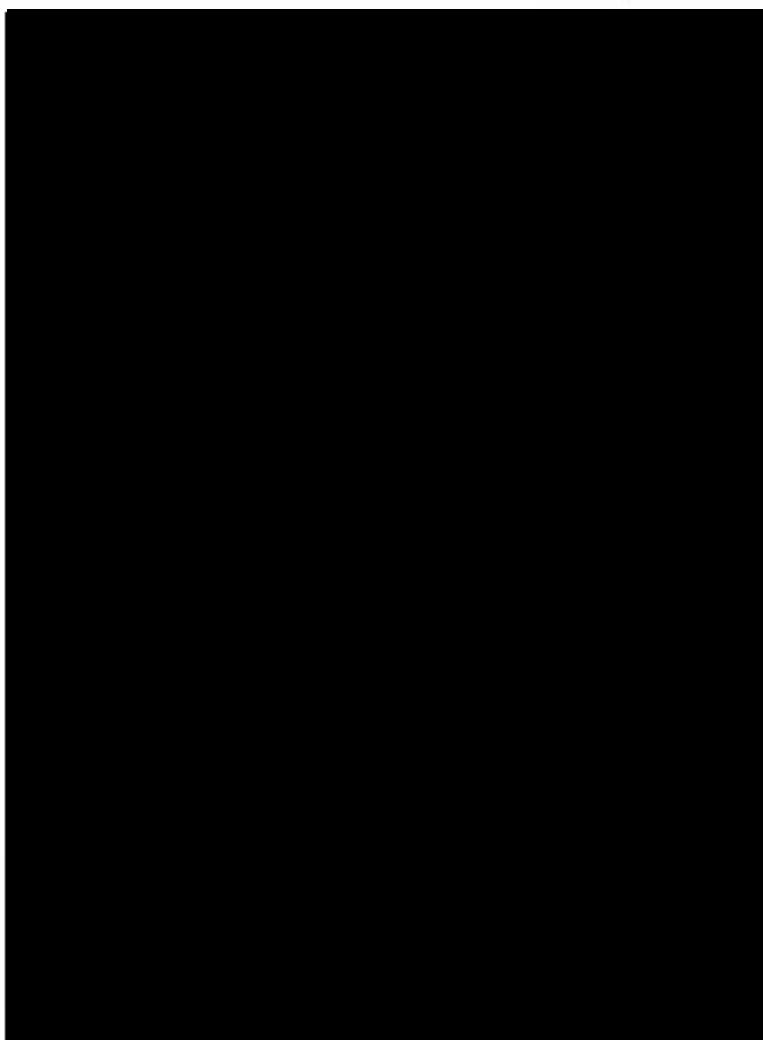


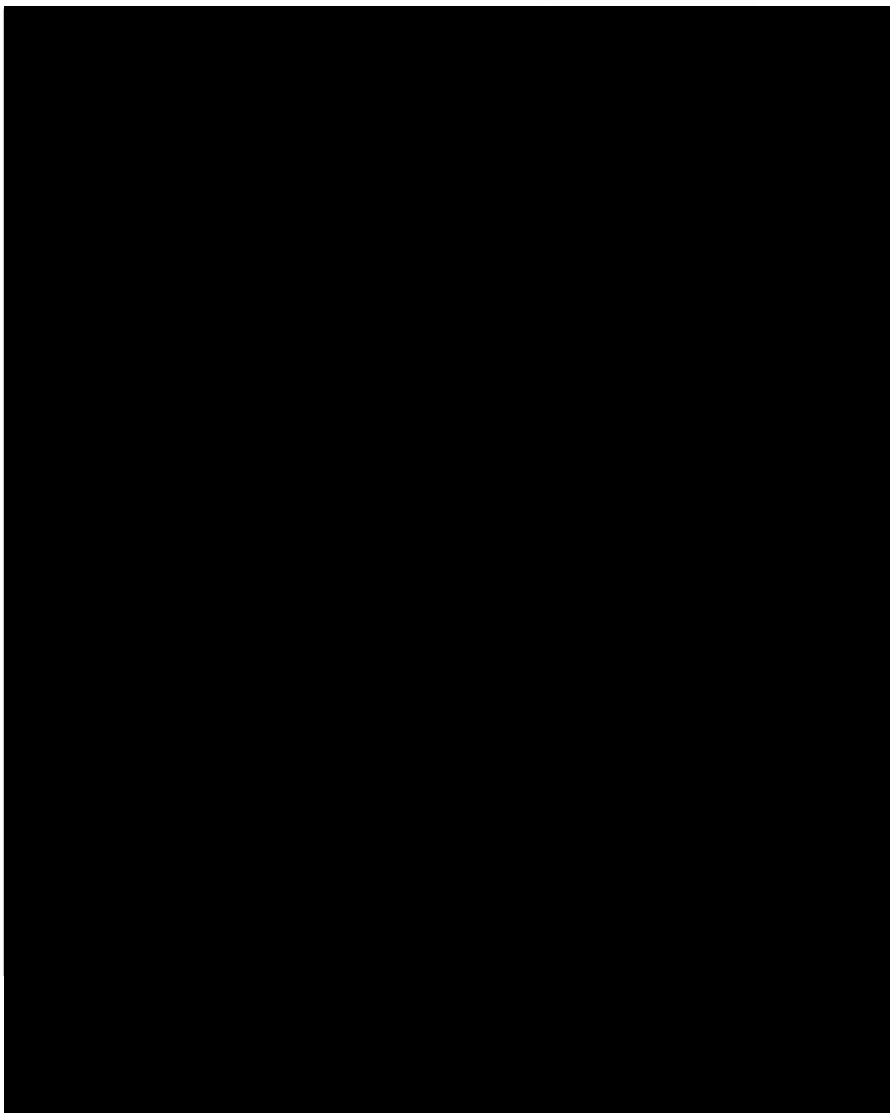


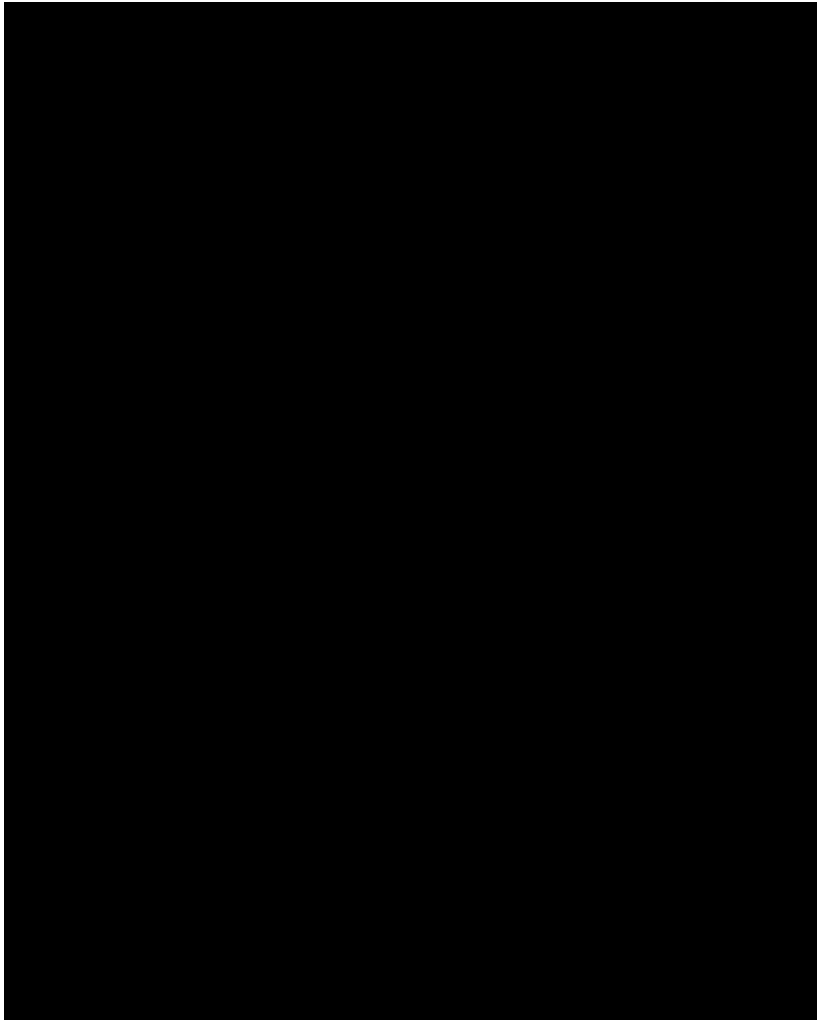


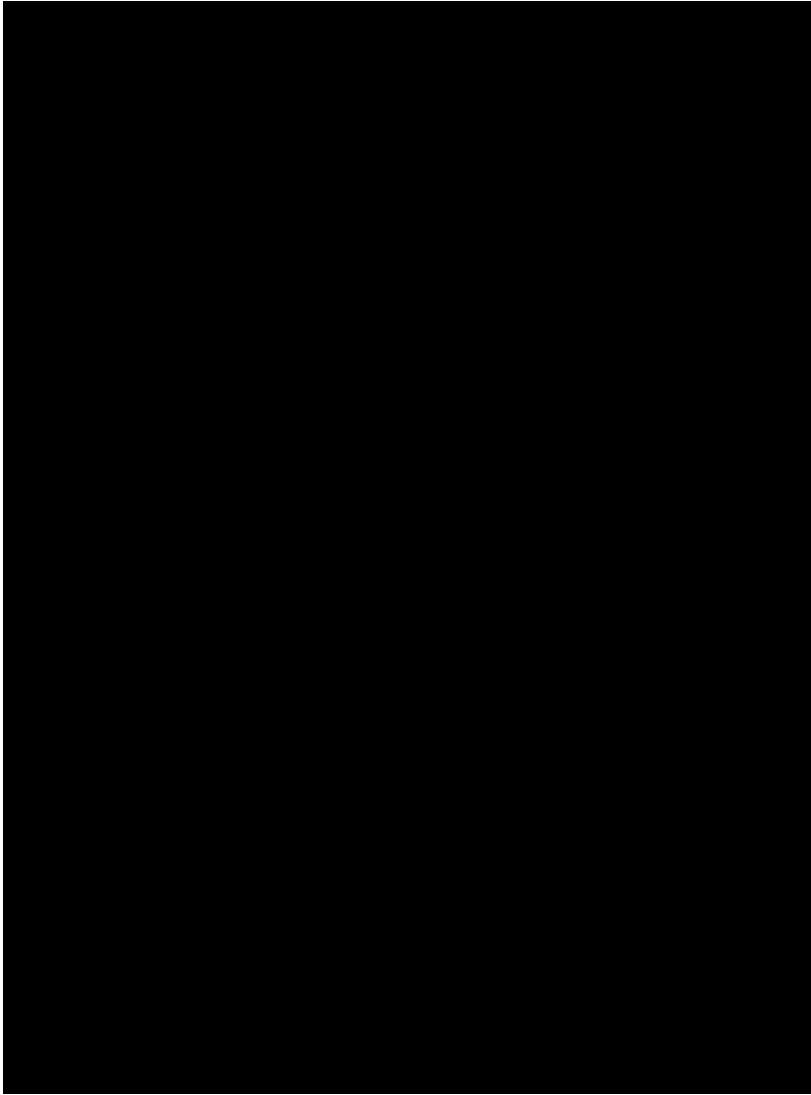


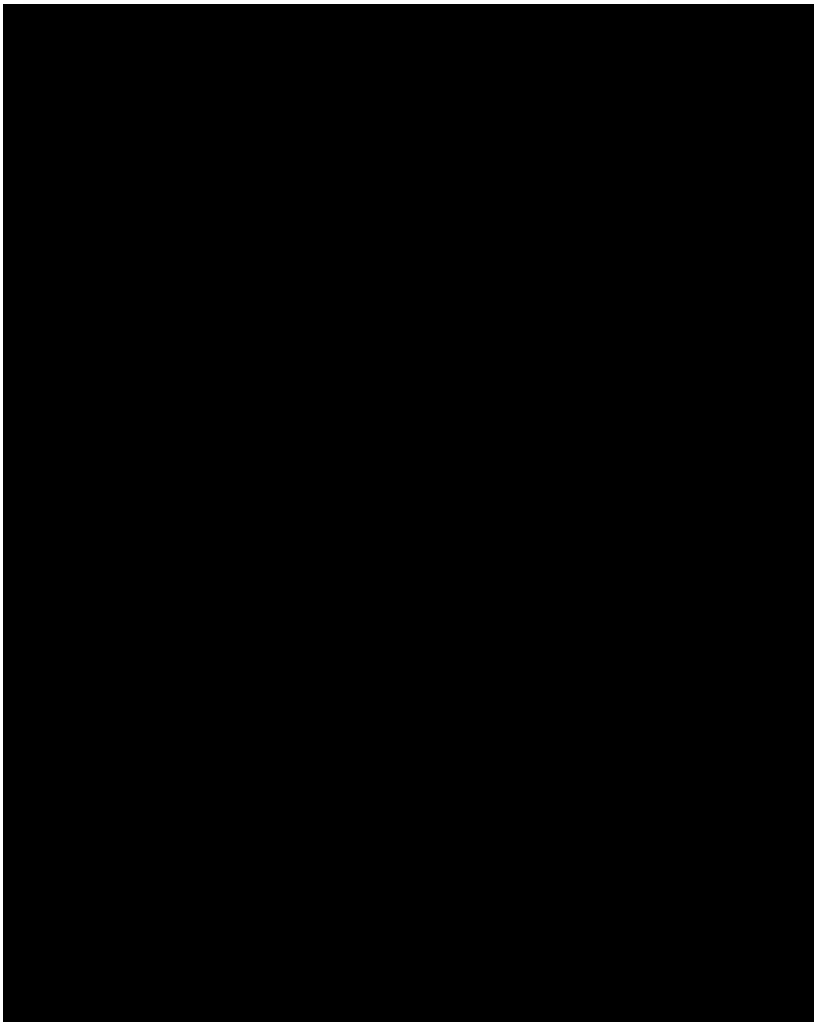


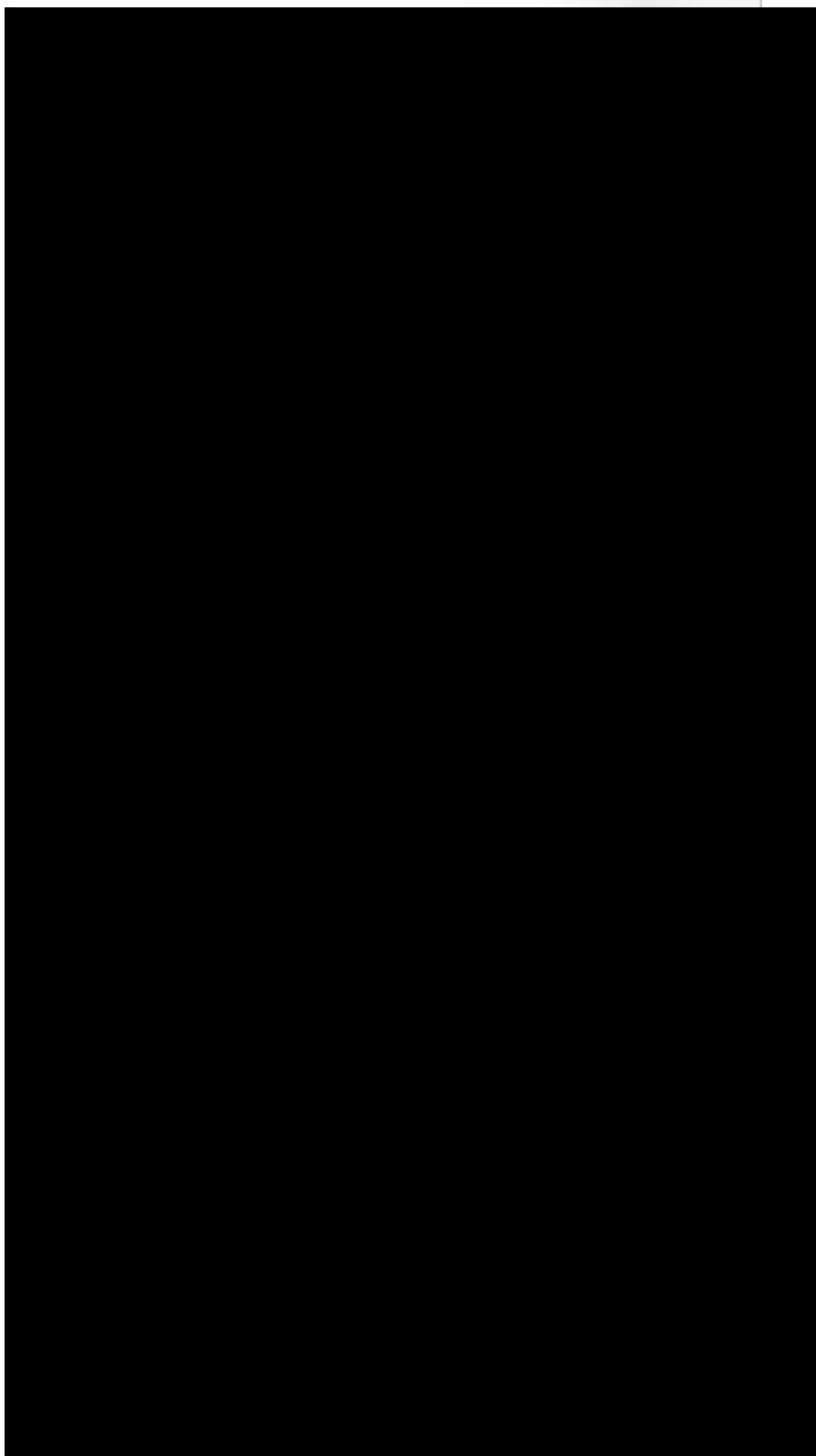


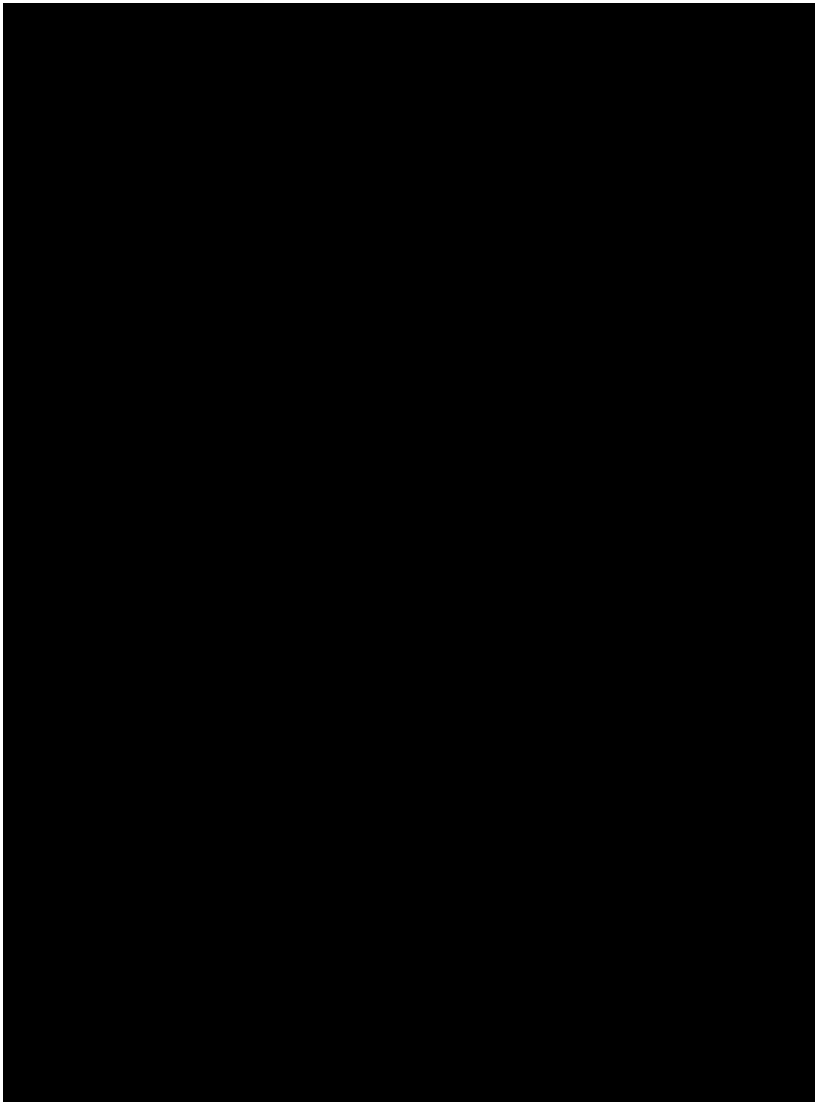


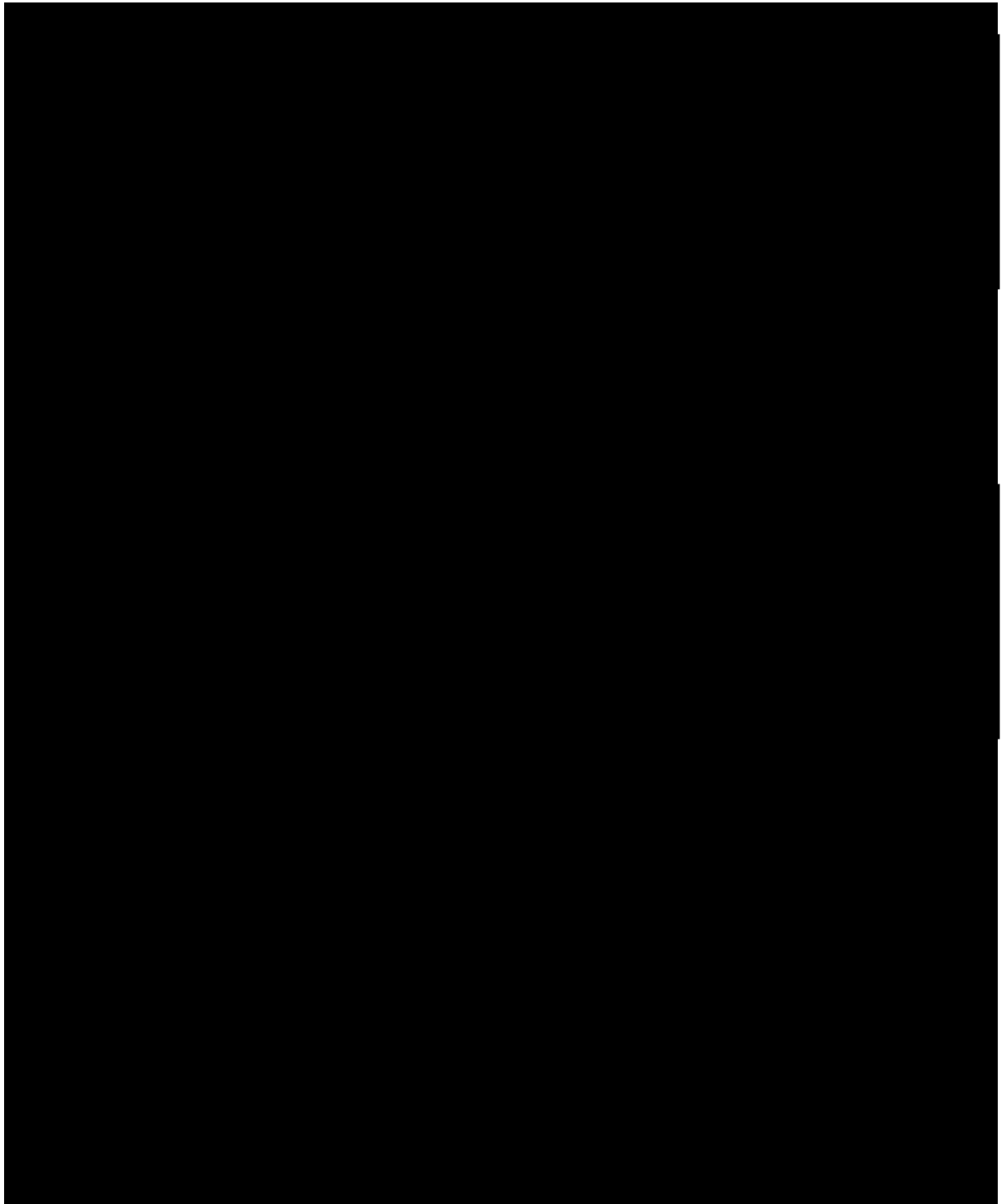


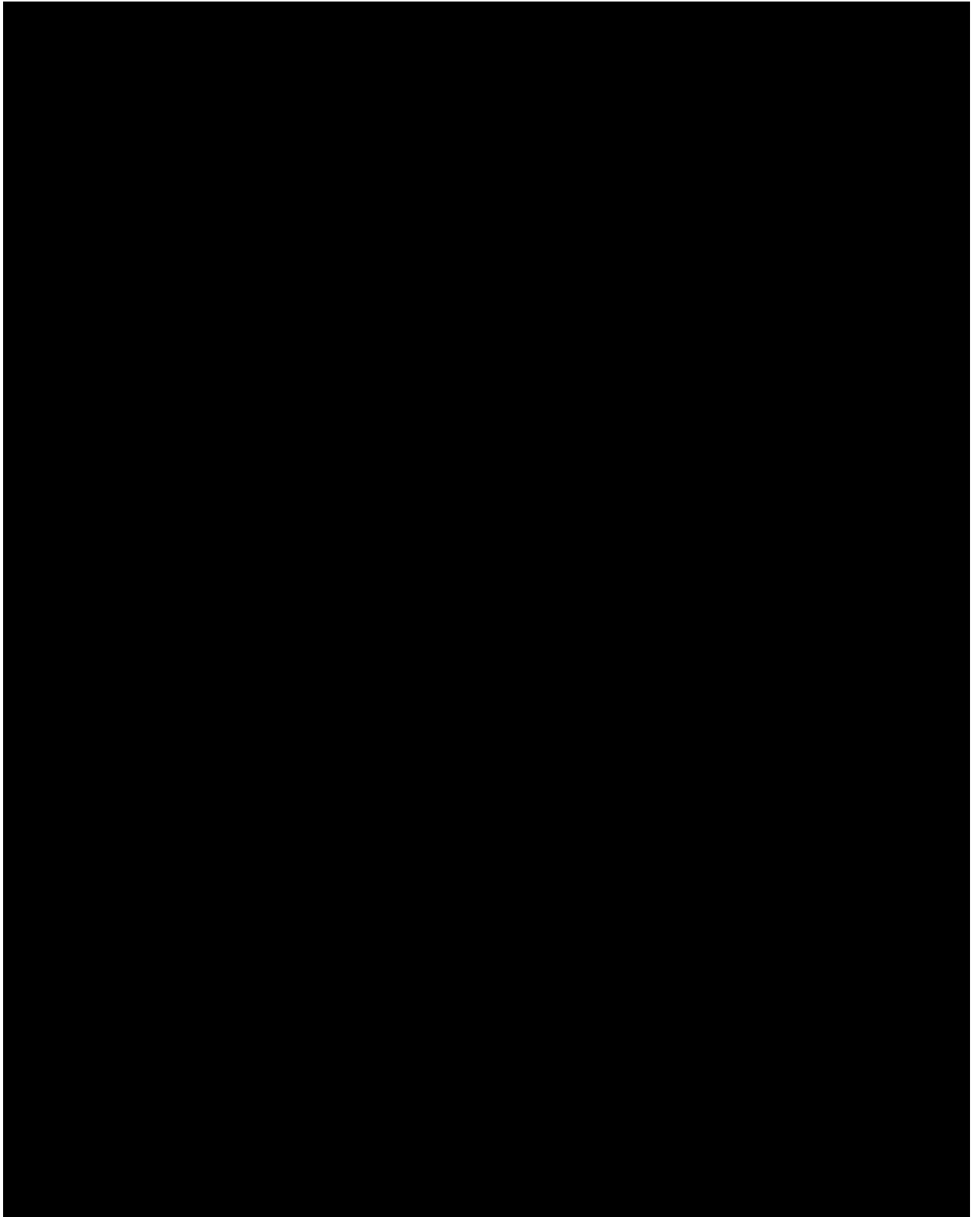


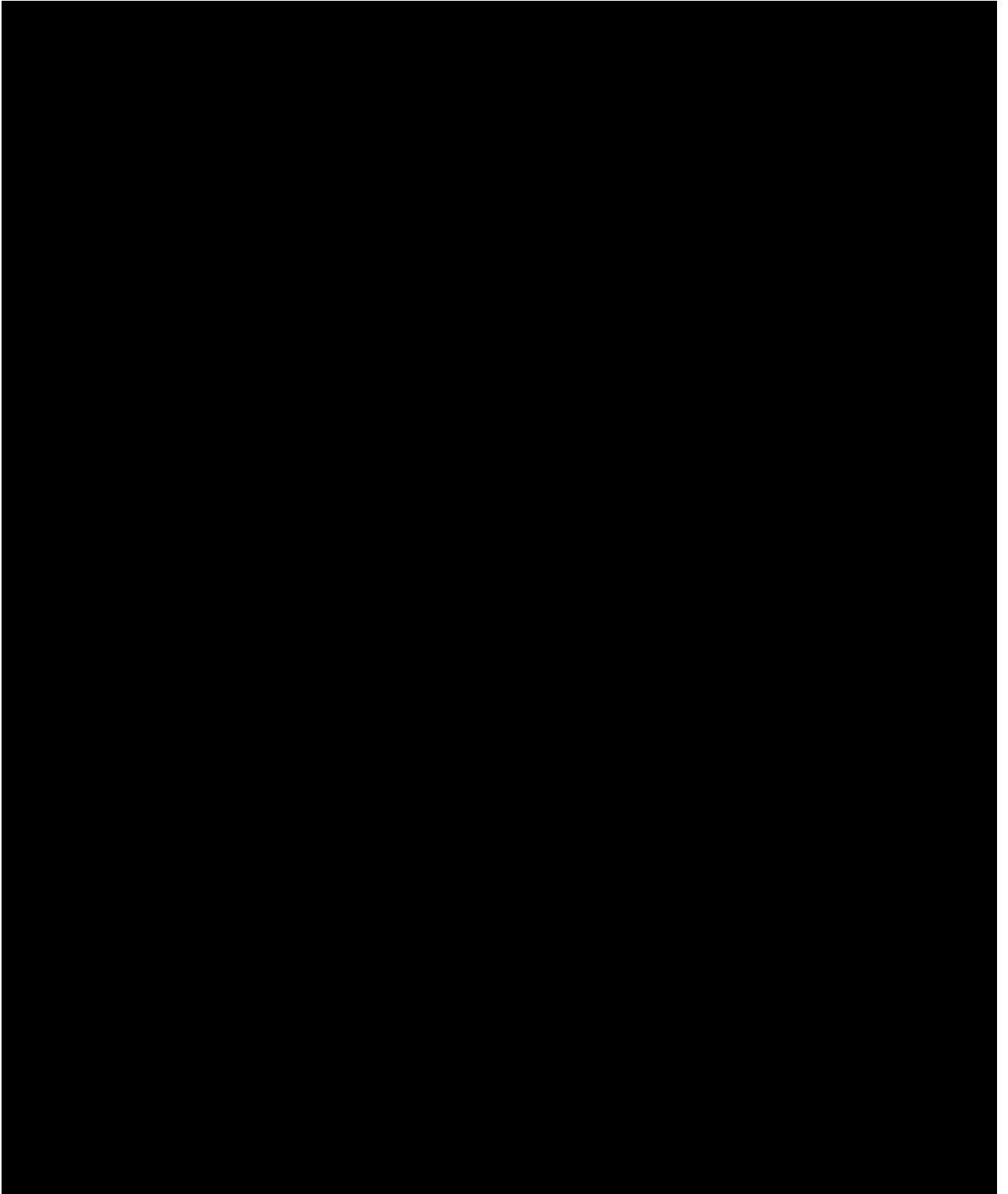


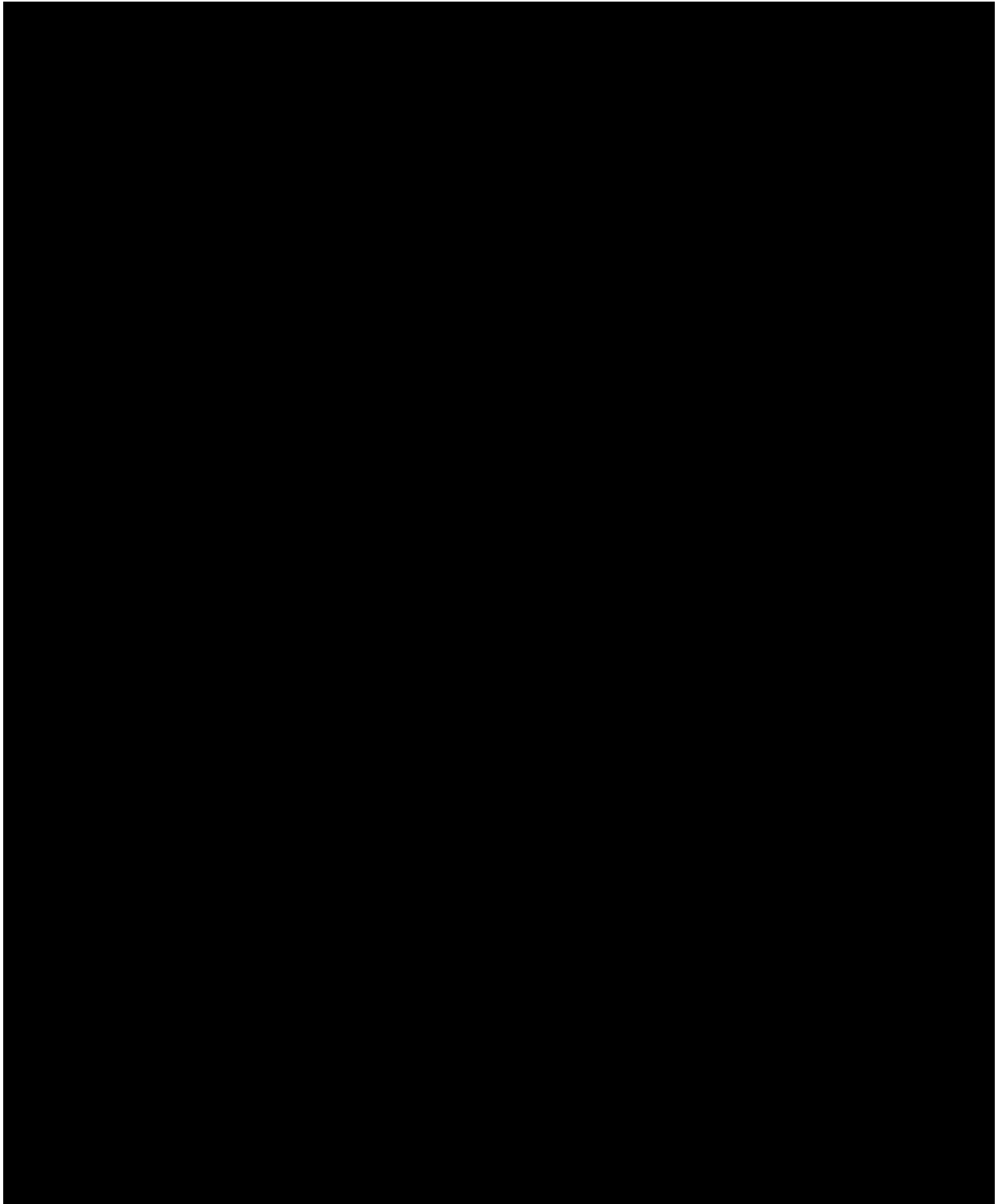


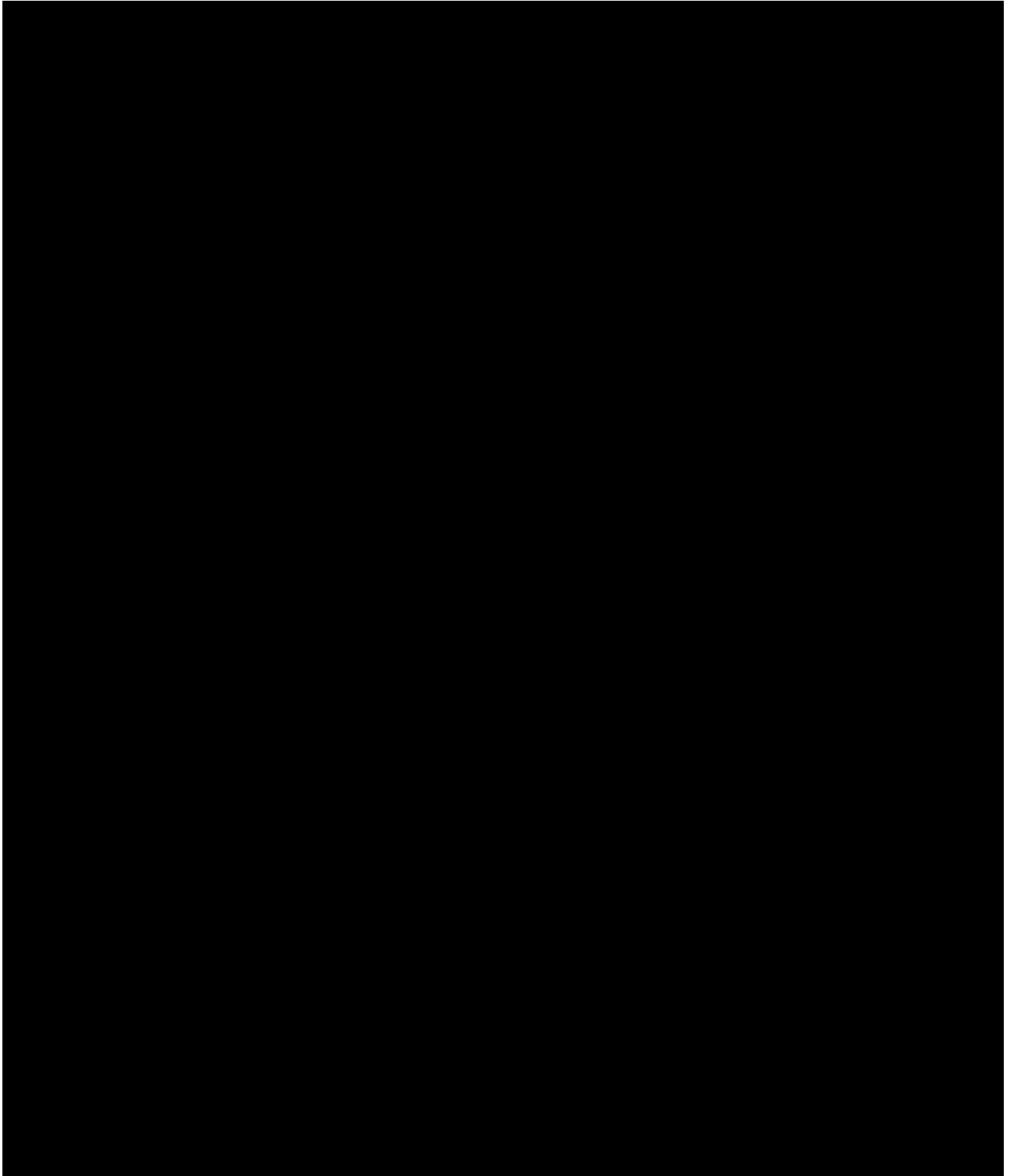


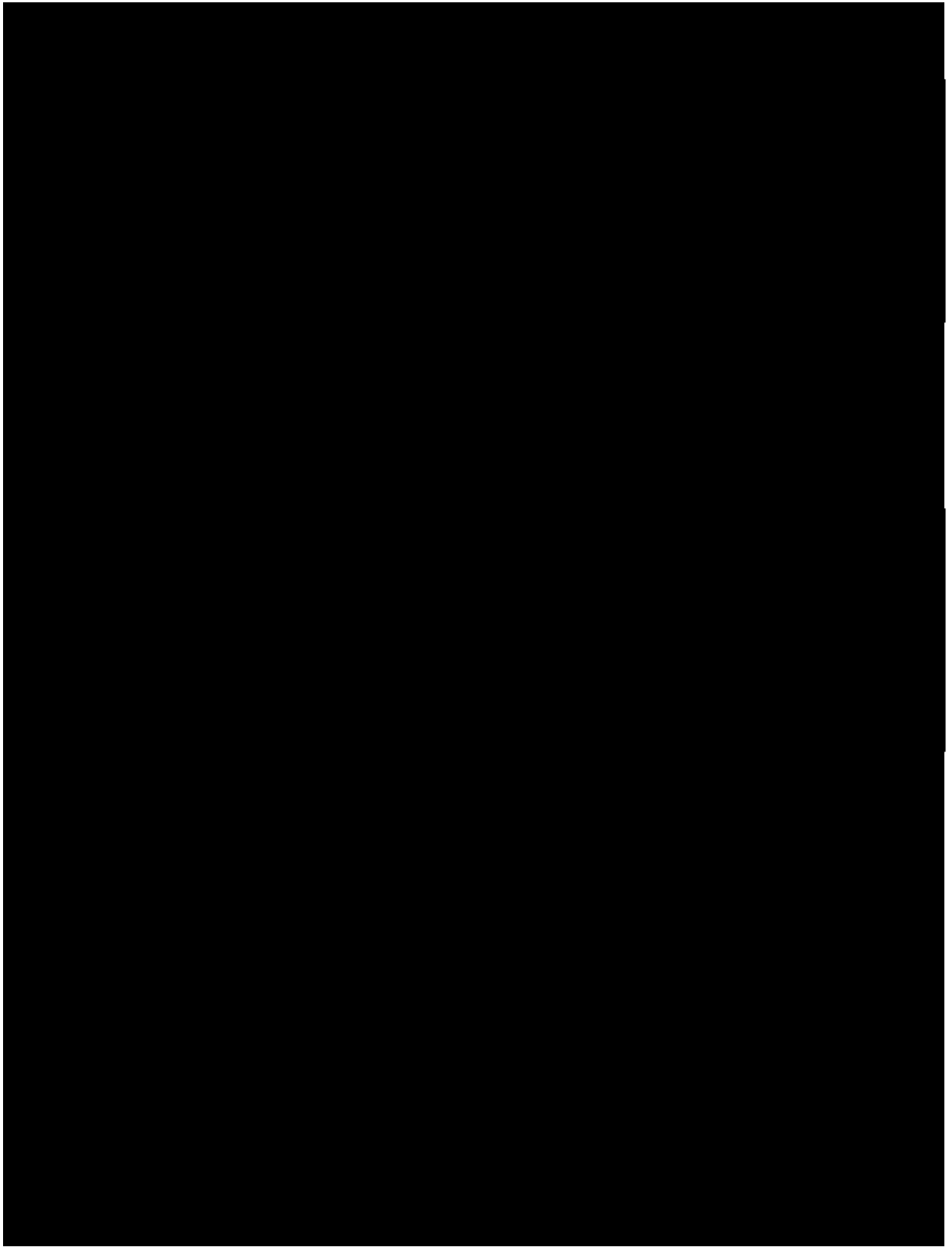




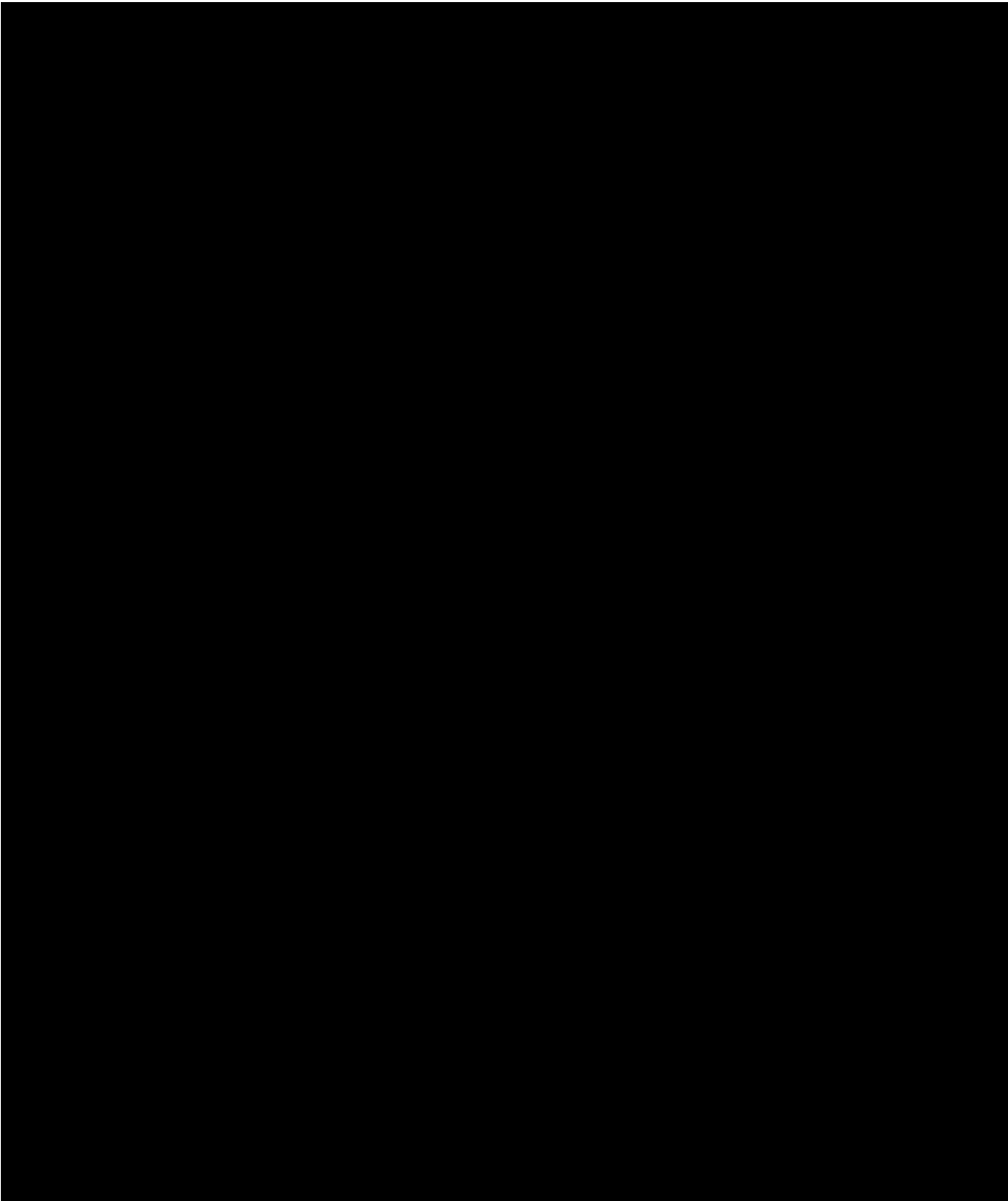


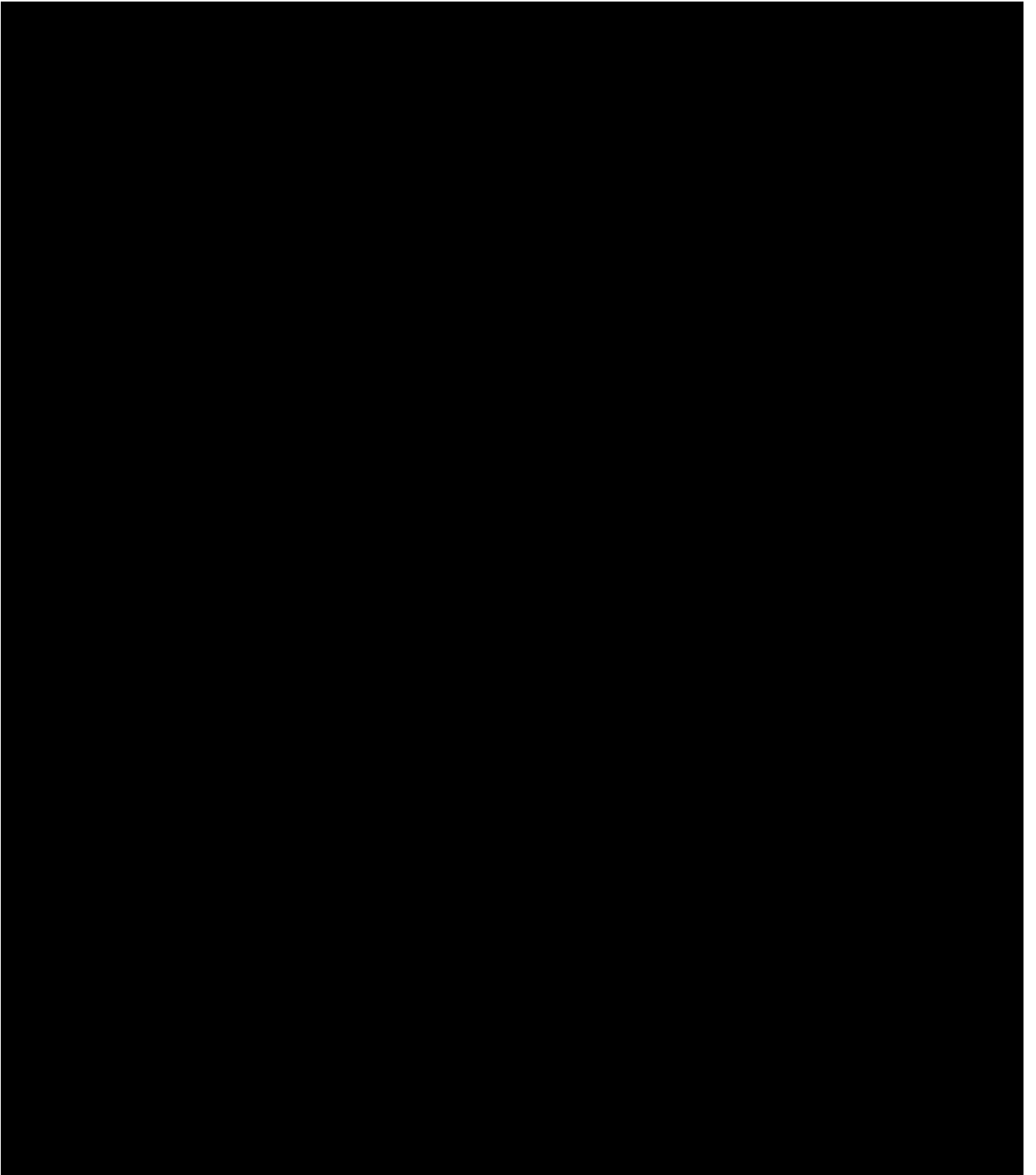


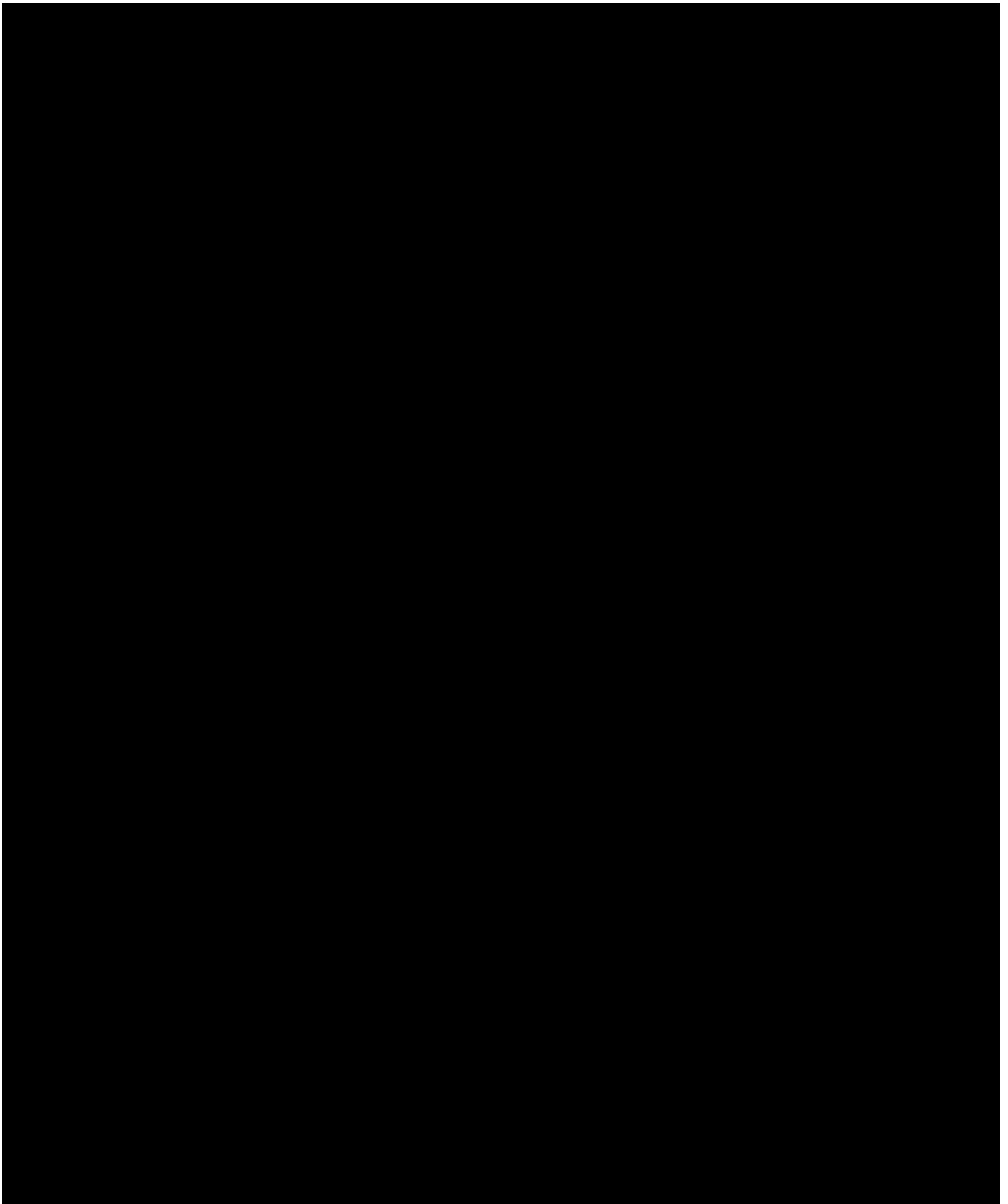


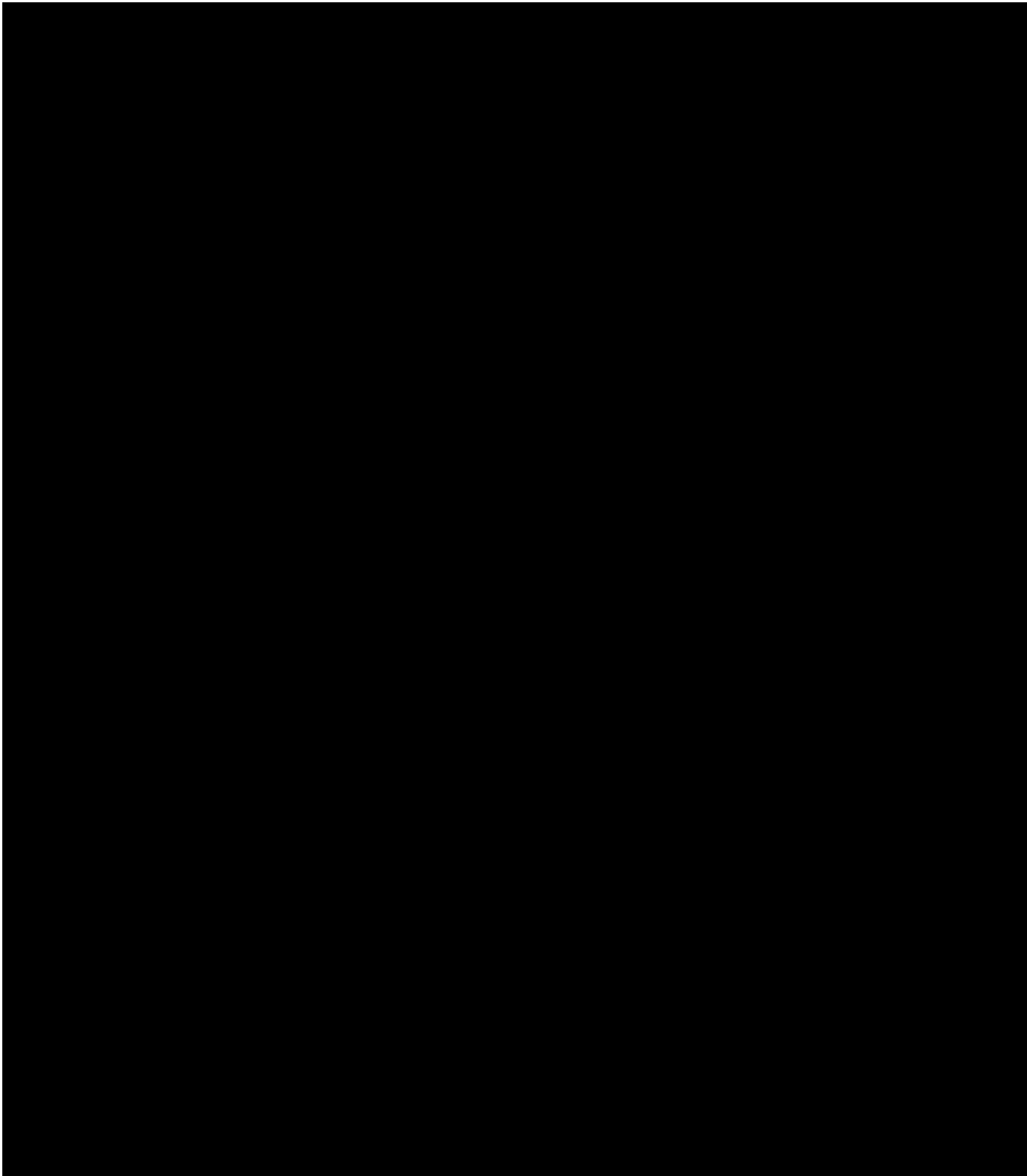


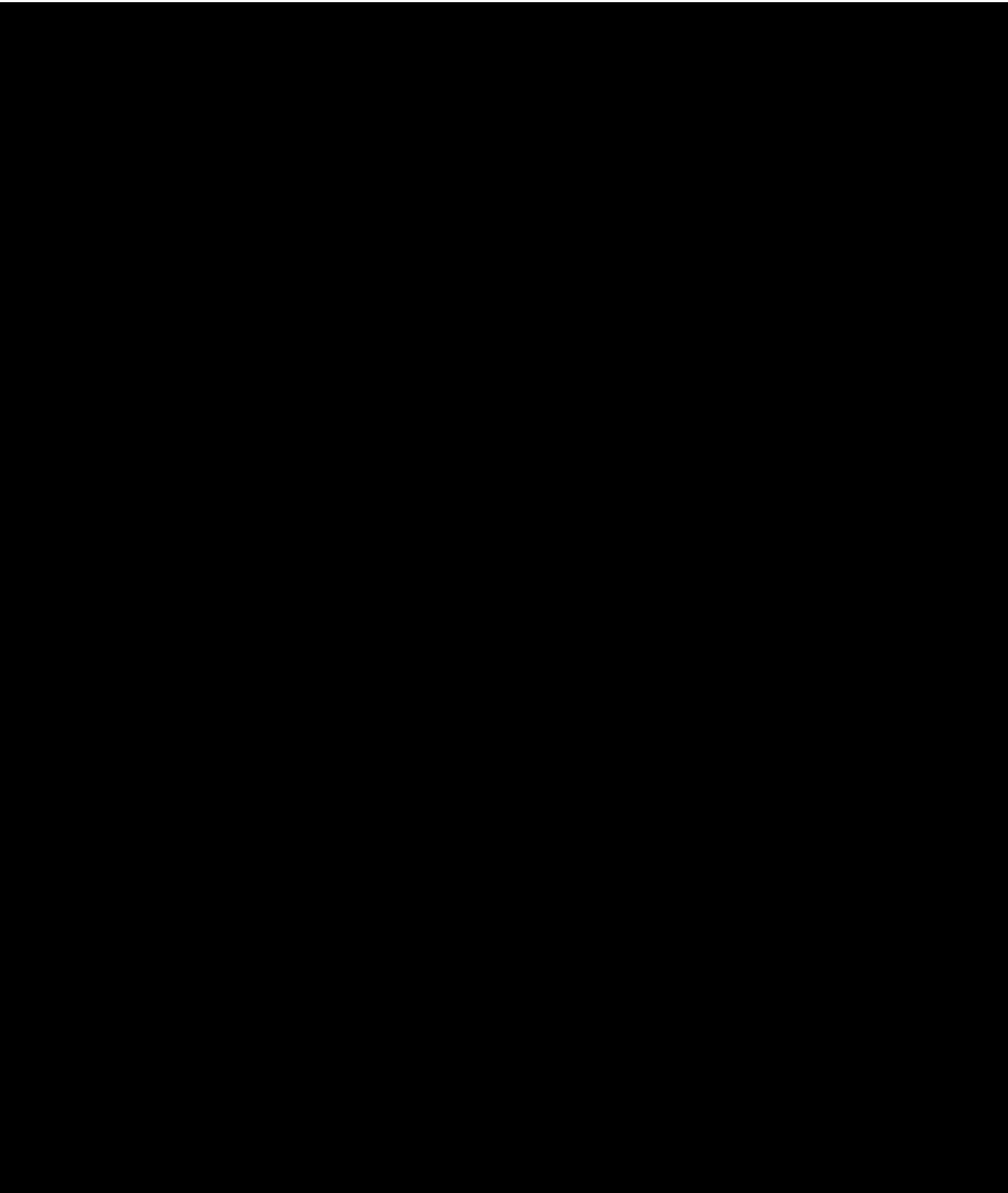


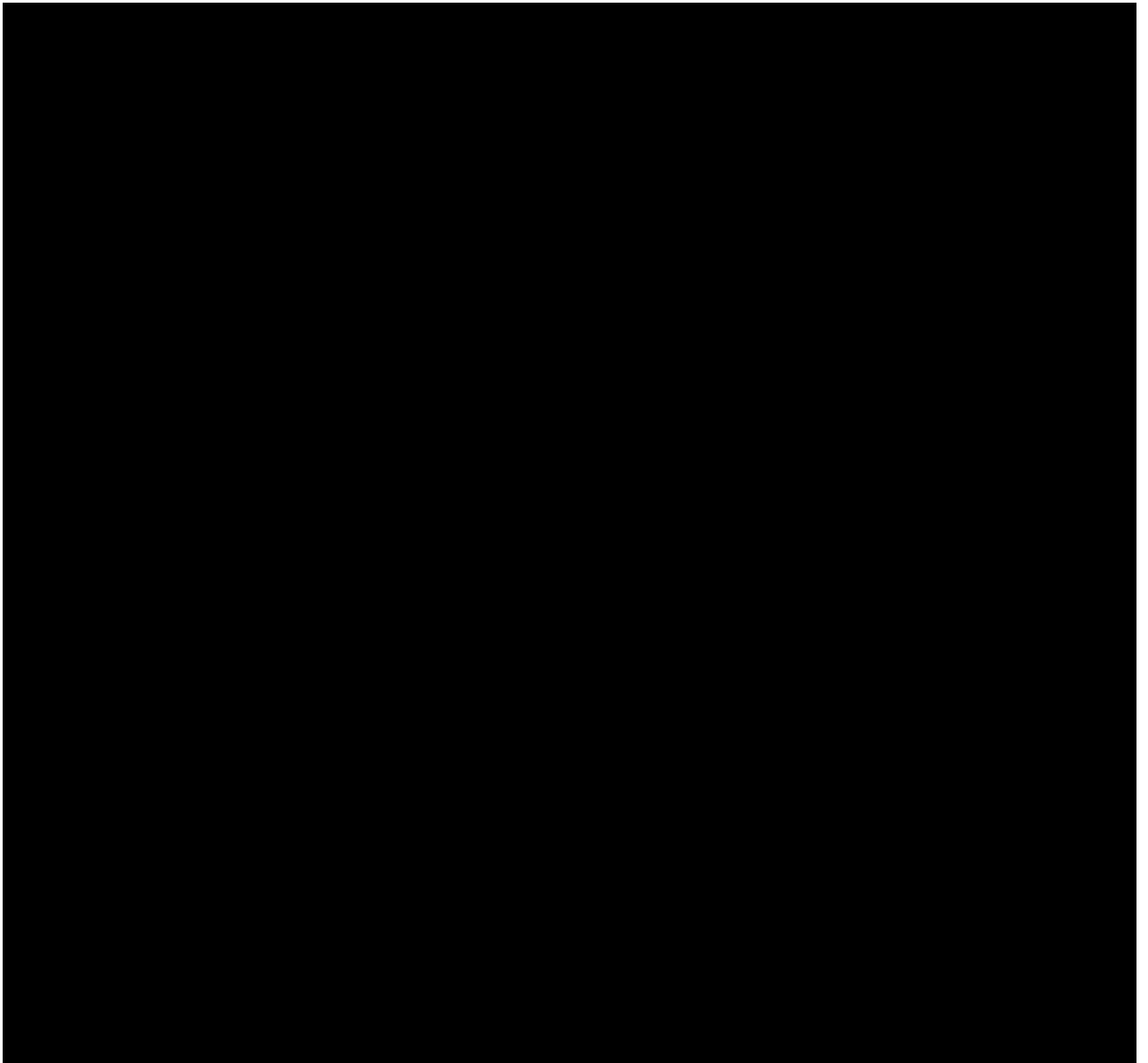


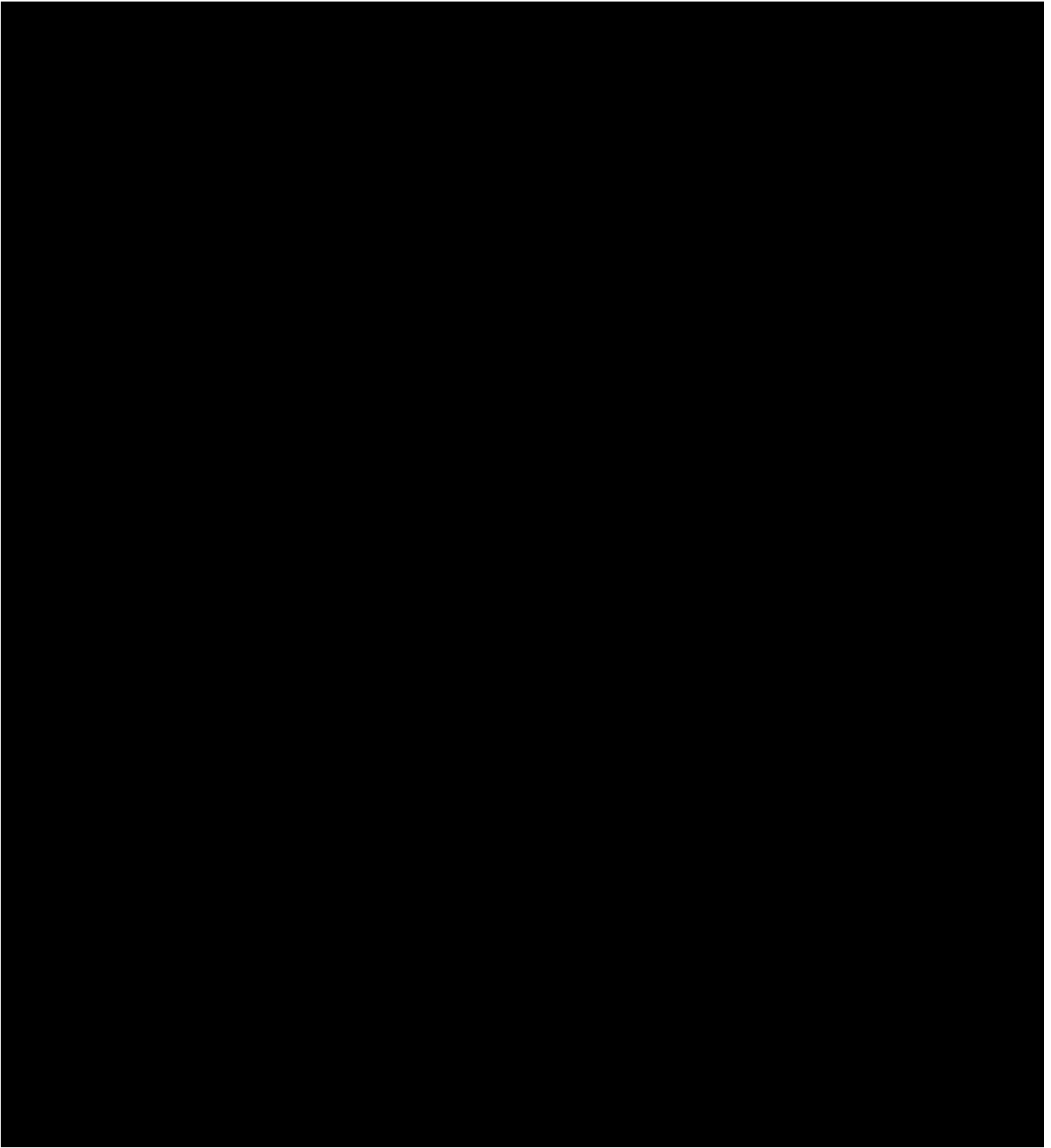


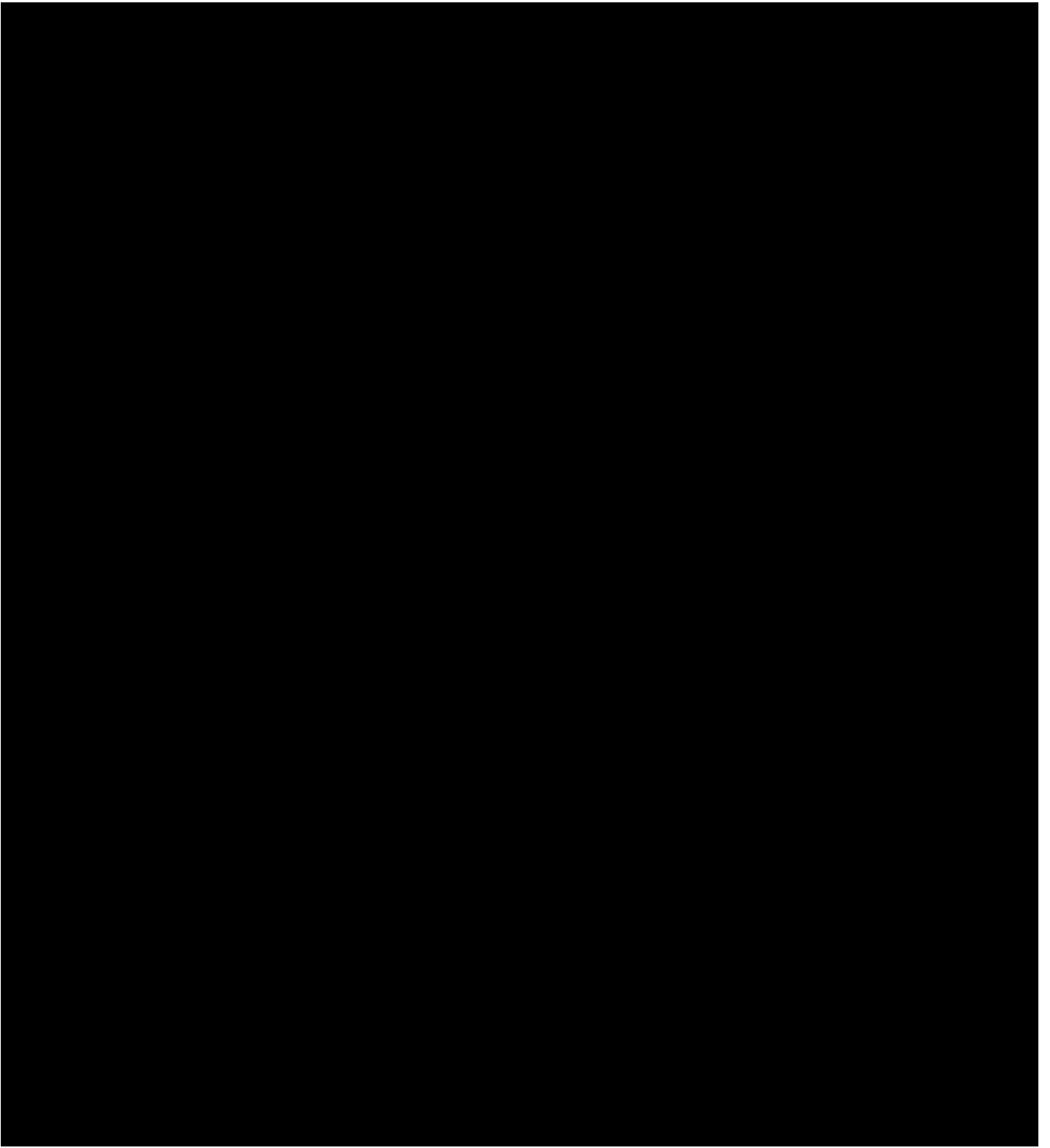


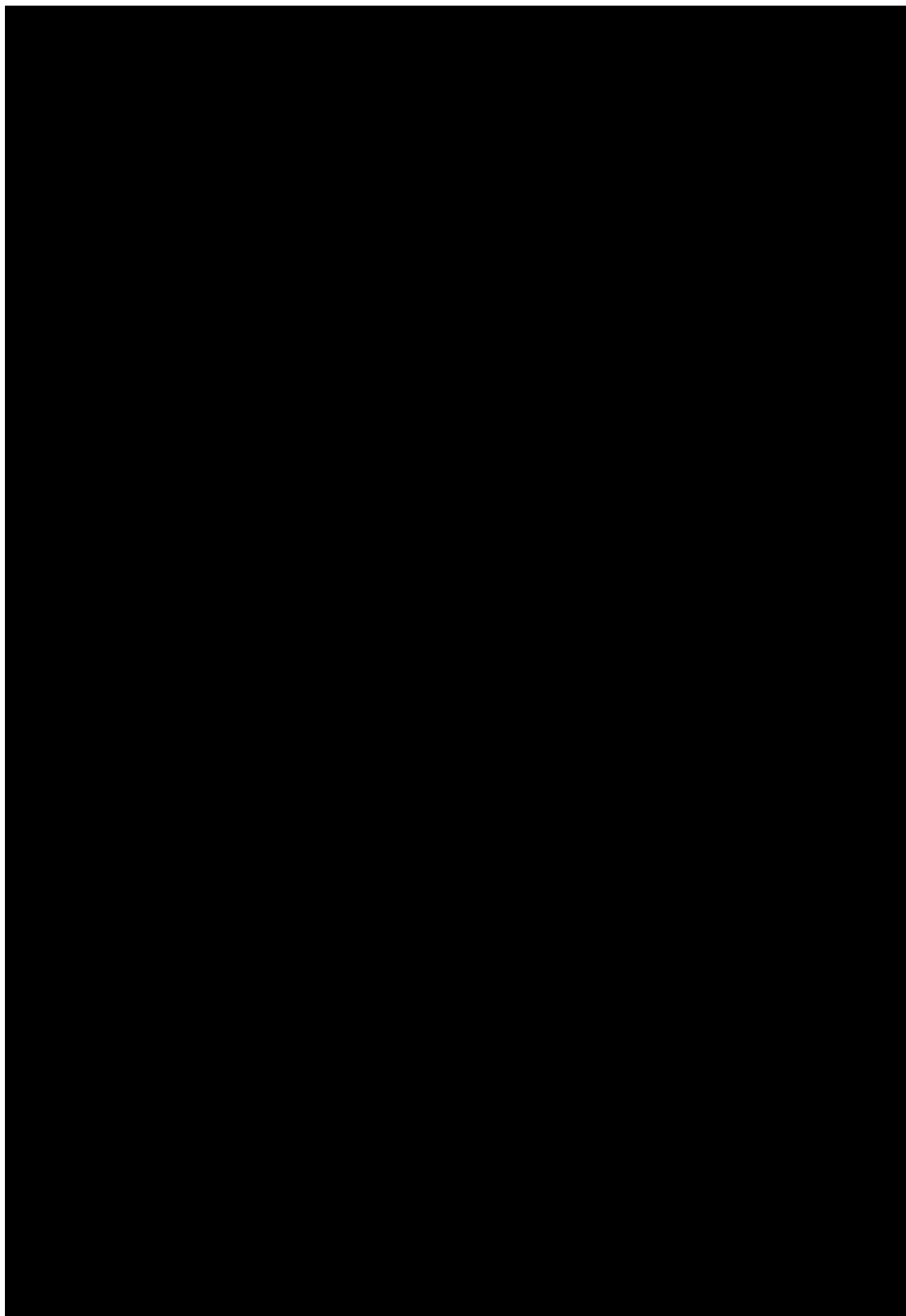


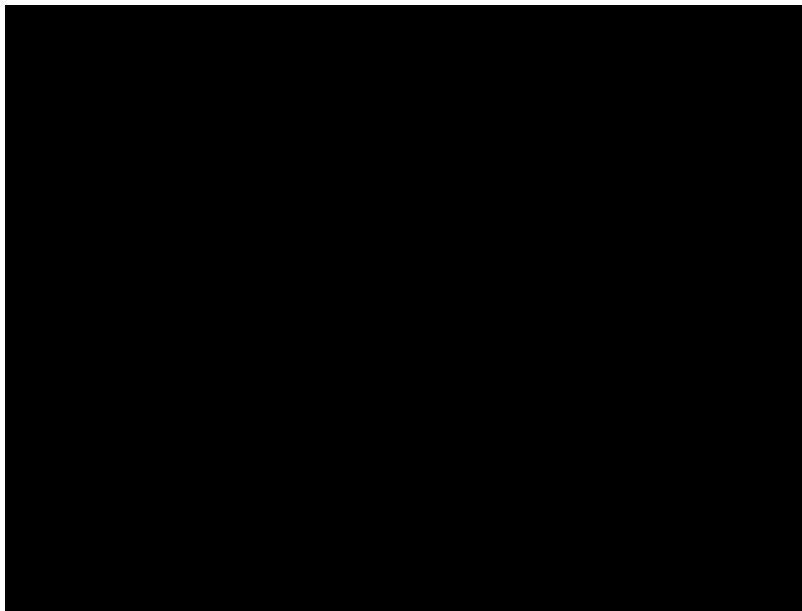












CORE UNIT 5

DHP 065

Conduct psychological interventions within a healthcare context to change behaviour of individuals or groups.

CASE STUDY

Implementing a Healthy Eating Behaviour Change
Intervention for Individuals with Schizophrenia

The following case study outlines a behaviour change intervention targeting healthy eating within several mental health units operating under the umbrella of a Care Quality Commission (CQC) registered organisation. The organisation operates a number of registered mental health units and other residential services in the North London area.

Background

Antipsychotic medication is the most common form of treatment for schizophrenia, evidence has highlighted the efficacy of anti-psychotic medication in treating the symptoms of psychosis and bringing about improvements in the course and outcome of the condition (Zygmunt, Olfson, Boyer, & Mechanic 2002). However, anti-psychotic medications have also been associated with a range of side effects, with around 75% of individuals prescribed anti-psychotic medication experiencing some form of side effects (Coffey, 1999). The nature, severity and extent of these side effects vary widely among individuals, but weight gain remains a frequent concern (Kurzthaler & Fleischhacker, 2001). Individuals gain an average of 13lbs in the first two months of taking antipsychotic medication and this continues over the first year. In fact, 29% of males and 60% of females with severe and enduring mental health issues are obese, compared with 17.7% of men and 28.5% of women overall (Dau- mit et al., 2003). This has been associated with serious health risks, as when compared to the general population, individuals diagnosed with schizophrenia are twice as likely to develop diabetes (Bailey, Thorpe & Smith, 2013), three times more likely to develop hypertension (Rethink Mental Illness, 2013), three times more likely to die from coronary heart disease (Osborn, 2007), ten times more likely to die from respiratory disease (Joukamaa et al. 2001), four times more likely to die prematurely

(Newman & Bland, 1991), and on average die twenty years earlier than the general population (Brown, Kim, Mitchell & Inskip, 2010). Public Health England have recently reported a systematic review of evidence of obesity in mental health units. A key finding of this review was that obesity is extremely prevalent amongst in-patients with levels at around 80% (Public Health England, 2017). Research indicates that this is linked to poor diet and a lack of active lifestyle within these settings (Rough, 2014). Recent government policy has stressed the need for interventions to address these issues in line with the National Institute for Health and Clinical Excellence (NICE) guidelines (Stegenga, Haines, Jones, & Wilding, 2014). This intervention therefore involved working alongside mental health professionals to deliver a healthy eating intervention for individuals diagnosed with schizophrenia.

Addressing behaviour change around health eating remains an imperative objective, as individuals suffering from schizophrenia often have little or no insight into their illness (Appelbaum & Grisso, 1995). They may not consent to treatment, and this can lead to sectioning under the Mental Health Act (1983), resulting in a lack of engagement and trust towards health care professionals, due to this, their overall well-being and physical health can often be overlooked (Acil et al., 2008).

Intervention component selection and theoretical underpinnings

As a consequence of this unmet need Senior Management within the intervention setting made the decision to adapt the NHS Health Trainer Scheme (Michie et al., 2008) in order to improve healthy eating in this client group. Health Trainers are recruited from the local community and their role includes supporting individuals from “hard to reach groups” to change their behaviour as they are marginalized from

health care services (Department of Health, 2008). The goal of Health Trainers is to provide equitable healthcare to these groups. The Health Trainer Scheme has been successfully implementing since 2004 (Michie et al., 2008), the organisation that I work for were eager to pioneer the application of this scheme, as it had not been implemented or evaluated within a mental health setting before. In order to deliver the intervention effectively I spent four days shadowing Health Trainers from Westway Trust's Westminster, Kensington & Chelsea boroughs. This expertise was extremely valuable when I attempted to deliver the intervention within my workplace.

Health psychology theory should be utilised to encourage mental health inpatients to improve their health and well-being (Wearden, 2014). The support that Health Trainers provide, is based on behaviour change techniques grounded in Health Psychology theory (Michie, et al 2008). Michie et al (2008) researched the evidence pertaining to the most effective techniques that help people change their behaviour, providing an essential framework of techniques to include in the intervention:

- ☐ Deciding to change (Rollnick et al., 1999)
- ☐ Goal setting (Carver and Scheier, 1998)
- ☐ Action planning (Sniehotta, Scholz & Schwarzer, 2005)
- ☐ Contracts (Kanfer & Goldstein, 1991)
- ☐ Self-monitoring (Bandura, 1998)
- ☐ Getting support (Wing, & Jeffrey, 1999)
- ☐ Increasing confidence to change (self-efficacy) (Schwarzer & Fuchs, 1995).

- Rewards (Skinner, 1969)
- Setbacks (Prochaska, Norcross & Diclemente, 1994).
- Realistic outcome expectancies (Rothman, 2000)
- Coping with difficult situations and 'if-ten' plans (Marlatt, 1996; Gollwitzer, 1999; Webb & Sheeran, 2006).
- Building habits (Aarts, Paulussen & Schaalma, 1997).

The NHS Health Trainer model also integrates motivational interviewing (Miller & Rollnick, 1991) techniques, as a means to assess clients and encouraging people to change. Motivational interviewing is an evidence based, client-centred form of counselling initially developed to change behaviour in relation to alcohol addiction and substance misuse (Rollnick, Mason & Butler, 1999). Motivational interviewing denotes the way in which practitioners engage in conversations with their clients (Miller & Rollnick, 2002), by providing an awareness of the importance of working with the individual rather than imposing ideas and beliefs upon them. Systematic reviews, across a range of health domains, have highlighted the effectiveness of motivational interviewing in helping to facilitate positive behaviour change. For example, Rubak et al. (2005) found that motivational interviewing is more effective than traditional advice giving and psycho-education when targeting behaviour change in a wide range of long-term conditions, including psychiatric disorders, addiction and obesity. As the manager of a community based mental health ward I had over 8 years of experience in applying motivational interviewing techniques. This experience was supplemented by the motivational interviewing training provided on the professional doctorate at City, University of London.

I was able to utilise and expand upon the techniques listed above, adapting them for application in a mental health setting. The additional approaches integrated into the NHS Health Trainer Scheme included a cost-benefit analysis of eating more healthily and skills training in meal preparation. My experience of working in mental health had raised my awareness of the importance of Activities of Daily Living (ADL) skills in this setting. Here ADL skills refer to the tasks adults routinely carry out during daily living, including any activity performed as part of self-care (such as feeding, bathing and dressing oneself) and leisure (Noelker & Browdie, 2013). Schizophrenia is characterised by a cyclical pattern of symptoms causing relapses and remissions. These symptoms can impact the ability of self-care and functioning and thus impact upon ADL skills (Tungpunkom, Maayan & Soares-Weiser, 2012). Individuals diagnosed with schizophrenia often experience challenges when selecting and preparing meals (Connolly & Kelly, 2005) and my professional role involves managing and overseeing attempts to enhance ADL skills. I therefore felt it was important to integrate skills training into the intervention in order to provide clients with the practical skills required to prepare a health meal independently.

To further expand the intervention and enable discussions about healthy eating and the costs and benefits of doing so, an additional model of behaviour change was selected – the health belief model (Rosenstock, 1966, 1974). The health belief model is an attitudinal model of health decision making with its roots based in a socio-cognitive perspective. It posits that individuals will take action to avoid health risks based upon specific beliefs that include their perceived susceptibility to the risk and the perceived benefits and barriers to taking action. When perceptions of barriers are faint while severity, susceptibility and benefits are high, a prompt is

needed in order for the individual to take action, this can be referred to as cues to action (Michie, West, Campbell, Brown & Gainforth, 2014). Cues to action can be either internal, such as perceptions of weight gain or external, such as interacting with mental health professionals about the issue. Later versions of the theory incorporated the element of self-efficacy, which refers to the individual's belief in their own ability to take the required action (Rosenstock, Strecher, Becker & Marshall, 1988). An element which is already integrated into the NHS Health Trainer Scheme.

This health belief model has been applied across a number of health-related behaviours successfully, including screening (Tanner-Smith & Brown, 2010), diabetes (Wdowik et al. 2001) and diet and exercise (Wallace, 2002). Research applying the model within mental health settings is however, relatively scarce with much of the prevailing literature focusing on use of the model in predicting adherence (Perkins, 2002). This research suggests that the health belief model may be an expedient framework for conducting research in this area (Henshaw & Freedman-Doan, 2009). Critics have however, suggested that it displays inadequate distinctive rules, weak effect sizes of its components, reduced predictive capacity and uneven application when compared to alternative social cognition models (Armitage & Conner 2000). Furthermore, although the HBM can be used to derive interventions to change health beliefs and behaviours, it does not provide clear guidance as to how interventions can be best structured (Yarbrough & Braden 2001). Despite this the directors of the organisation remained eager for the intervention to utilise the HBM, as they felt it was an appropriate model for this population.

In addition to using health psychology theory to select appropriate behaviour change techniques, all clients had to be risk assessed and their ADL skills assessed. This was an essential requirement as many of the service users who were due to take part in the intervention were forensic patients, including those convicted of violent offences. The standard risk assessment utilised by the organisation was used to assess factors including whether a bladed instrument had been used during the index offence and whether the service users had recently attacked staff members or other service users.

Planning and delivery of the intervention

Pilot intervention

A pilot intervention phase was conducted with six clients to assess the suitability of the planned intervention for this population. For a detailed description of the pilot intervention please refer to Appendix A.

Final intervention

An intervention pack was designed and provided to each client (Appendix b), which also included leaflets and materials on healthy living published by the British Heart Foundation. The intervention was a face-to-face, weekly 30-60 minute session, for six consecutive weeks, plus one face-to-face/telephone maintenance session 6 months later. All sessions were delivered by the Trainee Health Psychologist. An overview of the activities included in each session can be found in Table 1.

Table 1. Activities within each session

| Session | Content | Length of time |
|-----------|--|----------------|
| Session 1 | <ul style="list-style-type: none"> <li data-bbox="603 342 1134 383">□ Introductions and rapport building <li data-bbox="603 443 1219 696">□ Initiating discussions about the physical and psychological consequences of high weight and poor diet – cost-benefit analysis <li data-bbox="603 757 1102 1267">□ Development of a support plan: <ul style="list-style-type: none"> <li data-bbox="699 853 995 893">○ Risk assessment <li data-bbox="699 954 922 994">○ Goal setting <li data-bbox="699 1055 979 1095">○ Problem solving <li data-bbox="699 1155 970 1196">○ Action planning <li data-bbox="699 1256 935 1296">○ Commitment <li data-bbox="603 1335 991 1375">□ Introduce the food diary <li data-bbox="603 1435 975 1476">□ Baseline assessments | 60 minutes |

| Session | Content | Length of time |
|-------------|--|--|
| Session 2-6 | <ul style="list-style-type: none"> <input type="checkbox"/> Rapport building <input type="checkbox"/> Continuing the discussions about the physical and psychological consequences of high weight and poor diet. <input type="checkbox"/> Skills training – cooking and preparing healthy meals <input type="checkbox"/> Review food diary <input type="checkbox"/> Review goals <input type="checkbox"/> Problem solving <input type="checkbox"/> Action planning <input type="checkbox"/> Commitment <input type="checkbox"/> Follow-up assessment (session 6 only) | 30 minutes each. (session 6 – 60 minutes) |

| Session | Content | Length of time |
|---------------------|--|----------------|
| Maintenance session | <ul style="list-style-type: none"> <input type="checkbox"/> Continuing the discussions about the physical and psychological consequences of high weight and poor diet. <input type="checkbox"/> Review goals <input type="checkbox"/> Problem solving | 60 minutes |

Session 1

Much of session 1 was about building trust and rapport with the client. After baseline measures were taken, I set about developing support plan for each client, which included the risk assessment. We discussed the individuals' current eating habits, using the Eat Well Plate as a prompt for the discussion. This allowed us to generate

a list of possible behaviours to change and goals to set. While doing so I would review their ADL skills and initiate discussions about their understanding and knowledge of healthy eating, the physical and psychological consequences of being overweight and having a poor diet. Combined with the risk assessment, this helped inform how information could be delivered in an easy and comprehensible manner, based on the capacity of the individual. During these discussions about healthy eating, an individualised cost-benefit analysis was undertaken with each patient. This involved the individual talking through the advantages and disadvantages of changing or not changing their behaviour. This was where the HBM (Rosenstock, 1966) was integrated into the NHS Health Trainer Scheme. Discussions would focus on susceptibility to illness and investigate the client's beliefs about their risk of developing an illness due to their unhealthy diet and the severity of the illness. The costs and benefits involved in carrying out the behaviour were also discussed. Cues to action were highlighted through discussion of the physical and psychological consequences of a poor diet, such as constipation and indigestion.

I helped individuals to choose appropriate goals and set them utilising SMART goal techniques, an effective evidence-based, strategy for behaviour change (Swanson, 2016). After setting a goal, I assessed how confident the individual felt about achieving it, using a scale from 1 to 10 (with 10 being extremely confident and 1 being not confident). If confidence was low, we discussed the barriers to performing the behaviour and possible strategies to overcome them, and in some cases created more realistic goals. When the levels of motivation were high, I asked the individuals to write their goals down and sign the support plan to show commitment to change.

Sessions 2-6

In sessions 2-6 we reviewed their previous goals and where appropriate I provided praise for achieving the goal or for any steps towards success. If the goal was not achieved, I asked what barriers they experienced and how they could be overcome in the future. We then went back to the goal and amended it to make it more achievable, a new support plan was then created and signed by the client. If the goal was fully achieved, we discussed maintenance and stayed with what had been working to ensure that progress was stable for that particular goal. These sessions also included practical elements, such as cooking workshops. This provided an opportunity for clients to develop their skills, but also build rapport with the facilitator. Discussions about healthy eating, and individualised cost-benefit analysis was also undertaken throughout these sessions.

Maintenance session

This session was a 6 month follow-up to the main intervention, and recapped information that had been provided previously.

Motivational interviewing

Throughout the intervention I used motivational interviewing techniques, such as reflective listening (Miller & Rollnick, 2002), to improve communication and engagement levels while addressing ambivalence to change. I also incorporated the four guiding principles of motivational interviewing (i) resisting the righting reflex, (ii) understanding the service users own motivations, (iii) listening effectively and (iv) empowering the service user to feel capable of change (Rollnick, Miller & Butler, 2008).

A great deal of tact was required to conduct sessions in an informative and therapeutic way while ensuring that service users did not feel intimidated by the process. The majority of clients were from a forensic mental health setting and many had committed violent crimes and had been transferred to mental health wards from prisons or other secure correctional facilities. Furthermore, if delusional thought content or increased psychotic symptoms are noticed by professionals involved in their care, this is reported and could potentially result in lengthier in-patient admissions. For many, this can result in increased caution and reluctance to engage with healthcare professionals. During the trial intervention it became apparent that a number of service users were guarded and somewhat cautious during interactions, while others were suspicious and even hostile. In mental health settings professionals often perceive themselves as advocates for patient's healthcare. It can often be challenging to resist telling clients what to do. Traditional styles of communication can result in service user's resisting or denying that there is a need to change (Lai, Cahill, Quin & Tang, 2010) However, mental health patients do not always enter therapeutic sessions with a willingness to change, which often leads to confrontational, antagonistic and adversarial dynamics within mental health settings (Coffey, 1999). The role of motivational interviewing therefore became a vital element of the intervention. My experience of working within mental health allowed me to build up a rapport and develop a therapeutic relationship with service users.

Adapting the intervention for individual clients

This risk assessment highlighted a number pertinent challenge to the planned intervention. For example, for one client all kitchen knives needed to remain locked,

would need to be signed out and could not be handed over directly, without an immediate risk assessment being completed by his named nurse. I attempted to improvise the meal to one that did not require the use of a knife. It also soon became apparent that some patients had very limited cooking skills and thus running the intervention within this client group required a great deal of flexibility on my part. This illustrated the key practical and theoretical challenges to delivering this intervention. Service users that took part in the intervention included individuals with a history of extreme violence and the practical challenges of using cooking utensils with individuals who had a history of using bladed items as weapons was something that I needed to remain aware of throughout each session.

All of the sessions were individualised for each participant based on their performance and ability to comprehend the information provided. For those who struggled in relation to their concentration spans or input capacity, I would attempt to provide information in a more straightforward, comprehensible form with the use of picture cards, cues and games.

Evaluate the intervention

The following measures were taken at the beginning of session 1, again at session six and 6 months post intervention:

- ☐ Weight (kg)
- ☐ Height (cm)
- ☐ Body Mass Index (BMI)
- ☐ A discussion of eating habits, physical activity levels, alcohol and nicotine intake

- Physical and emotional wellbeing using the WHO5 Wellbeing Index (WHO, 1998)
- General Self-efficacy (Chen, Gully & Eden, 2001).

Twenty-four referrals were made for the intervention. However, sixteen individuals were unable to take part based on either the risk assessment, relapses to their mental health and presentation, or having previously worked with the trainee. Eight individuals completed the intervention. Due to the small sample size it was not appropriate to conduct any statistical analysis. The results indicated that all eight individuals who had taken part, had lower weight and BMI after participating in the intervention. Five of the participants reported higher levels of motivation and well-being. Four of the participants reported higher levels of self-efficacy. Six of the participants reported higher levels of physical activity. At six-month follow-up, six of the eight individuals had maintained their weight loss, with five individuals reporting higher rates of self-efficacy. An overview of the results can be found in Table 2.

Table 2: Pre and Post intervention scores.

| | Participant 1 | Participant 2 | Participant 3 | Participant 4 | Participant 5 | Participant 6 | Participant 7 | Participant 8 |
|-------------------------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|
| Baseline weight | 100kg | 99kg | 68kg | 77kg | 125kg | 82kg | 112kg | 155kg |
| Time 2 weight | 94kg | 98.5kg | 63kg | 74.5 kg | 122kg | 81.5kg | 109.5kg | 154 kg |
| Baseline BMI | 28.3 kg/m2 | 30.4 kg/m2 | 24.1 kg/m2 | 25 kg/m2 | 39.5 kg/m2 | 26.6 kg/m2 | 32.5 kg/m2 | 49 kg/m2 |
| Time 2 BMI | 26.6 kg/m2 | 30.3 kg/m2 | 22.4 kg/m2 | 23.7 kg/m2 | 38.5 kg/m2 | 26.5 kg/m2 | 31.8 kg/m2 | 48.7 kg/m2 |
| Baseline Well-being | 80 | 36 | 72 | 61.5 | 42 | 56 | 60 | 12 |
| Time 2 Well-being | 88 | 32 | 80 | 64 | 48 | 58 | 60 | 12 |
| Baseline Self-efficacy | 32 | 22 | 28 | 30 | 32 | 18 | 21 | 13 |
| Time 2 Self-efficacy | 36 | 20 | 36 | 14 | 34 | 22 | 19 | 08 |
| Baseline Motivation | 8 | 5 | 7 | 6 | 8 | 7 | 5 | 10 |
| Time 2 Motivation | 10 | 5 | 9 | 7 | 10 | 8 | 5 | 3 |

In addition to exploring the effectiveness of the intervention in terms of clinical, psychosocial and behavioural outcomes, organisational feedback was obtained from the directors of the service. Despite initial challenges, the overall intervention was viewed as a success. The Directors commented on the comprehensive and easily replicable nature of the intervention and as a consequence, I was asked to instruct other staff members in how to deliver the intervention. It was subsequently implemented on a number of wards, resulting in the organisation requesting that I conduct additional training in motivational interviewing to all staff (refer to Teaching and Training case study A). For a detailed reflective account of the delivery and implementation of the intervention please refer to Appendix C.

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Appendix A

Pilot intervention

A pilot intervention phase was conducted with six clients to assess the suitability of the planned intervention for this population. To facilitate participation and engagement the pilot intervention consisted of the patients from my work as I had already developed a therapeutic relationship with them based on trust, empathy and mutual understanding. Barriers that could impact upon delivery and effectiveness of the intervention became apparent and are exemplified by my interaction with one service user (AC). AC was a 42 year old male who has been residing within in-patient settings since being diagnosed with schizophrenia at the age of 17. His speech was monosyllabic and disjointed and he often appeared to respond to possible auditory and visual hallucinations. AC appeared to have a complete lack of motivation regarding his activities of daily living. During the workshop AC was asked to demonstrate what food he was currently able to prepare and while attempting to make beans on toast poured the beans into the kettle in an effort to heat them. At this stage it became apparent that I would need to deliver an intervention that would be consistent for all that took part, but also remain flexible enough for sessions to be individualised to take into account the vastly differing cognitive functioning for those taking part. Schizophrenia is characterised by varied symptoms for individuals diagnosed with the condition and these conditions can fluctuate markedly. It also confirmed the positive impact of motivational interviewing techniques when conducting the intervention, highlighting the importance of taking a collaborative, supportive and non-confrontational approach.

Appendix B
Intervention Pack.

Behaviour Change Intervention

Healthy Eating Goal Setting

Contents

Listed below are the stages of the Behaviour Change programme, these are subsequently detailed in full in the proceeding pages.

- Consent
- Individualised Details
- Assessment
 - Initial Assessment
 - Wellbeing Measure 1
 - Intervention: Individualised Healthy Eating Plan
 - Progress Reviews
 - Wellbeing Measure 2

 - Maintenance check (after 6 months)

Consent

Statement of Trainee Health Psychologist

- I have explained the programme to the client.
- I have explained that information will be securely stored in accordance with the Data Protection Act and BPS Guidance.

Signed: _____

Name: _____

Date: _____

Job Title: _____ Trainee Health Psychologist

Statement of Client

- I consent to participation in the Behaviour Change programme.
- I understand that data will be securely stored on paper and electronically.

Signed: _____

Name: _____

Date: _____

Service User Details

Last Name

First Name

MHA Status

Ethnicity

- | | |
|--|--|
| <input type="checkbox"/> A: White – British | <input type="checkbox"/> J: Asian or Asian British - Bangladeshi |
| <input type="checkbox"/> B: White – Irish | <input type="checkbox"/> K: Any other Asian background |
| <input type="checkbox"/> C: Other White Background | <input type="checkbox"/> L: Black or Black British - Caribbean |
| <input type="checkbox"/> D: Mixed - White and Black Caribbean | <input type="checkbox"/> M: Black or Black British - African |
| <input type="checkbox"/> E: Mixed - White and Black African | <input type="checkbox"/> N: Any Other Black Background |
| <input type="checkbox"/> F: Mixed - White and Asian | <input type="checkbox"/> O: Chinese |
| <input type="checkbox"/> G: Mixed - Any Other Mixed Background | <input type="checkbox"/> P: Any Other Ethnic Group |
| <input type="checkbox"/> H: Asian or Asian British - Indian | <input type="checkbox"/> Z: Not Stated |
| <input type="checkbox"/> I: Asian or Asian British - Pakistani | |

| | | | |
|---------------------------|--|-----|--------------------------------------|
| Mental health diagnosis | | | |
| Co-morbidity | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| Physical health diagnosis | | | |
| Gender | | | |
| Address | | | |
| DOB | | Age | |
| Mobile | | | <input type="checkbox"/> SMS allowed |
| Additional Information | | | |

Assessment Process

Initial Assessment

Employment status

- | | |
|---|--|
| <input type="checkbox"/> Employed full-time | <input type="checkbox"/> Self-employed |
| <input type="checkbox"/> Employed part-time | <input type="checkbox"/> Student |
| <input type="checkbox"/> Full-time carer | <input type="checkbox"/> Unemployed |
| <input type="checkbox"/> Response declined | <input type="checkbox"/> Volunteer |
| <input type="checkbox"/> Looking after home or family full time | <input type="checkbox"/> N/A – Offender Health |
| <input type="checkbox"/> Permanently sick/ disabled | <input type="checkbox"/> Other |
| <input type="checkbox"/> Retired | |
| <input type="checkbox"/> Alcohol | <input type="checkbox"/> Illicit substance use |
| <input type="checkbox"/> Diet | <input type="checkbox"/> Smoking |

Topics discussed

- ☐ Exercise
- ☐ Local Issue

Additional information

Physique

Height

Cm/ M/ Ft

Weight

Kg/St

Waist Circumference

Cm / Inch

Exercise

Number of 30 minute sessions of moderate exercise per week

Number of 20 minute sessions of Vigorous exercise per week

Diet

Type of Food

How many days last week
did you eat this kind of
food?

On average, how many
portions per day?

| | | |
|---|----------------------|----------------------|
| Fruit (e.g apples, bananas, mangoes, oranges) | <input type="text"/> | <input type="text"/> |
| Vegetables (e.g. carrots, broccoli, peas, okra, au- bergine) | <input type="text"/> | <input type="text"/> |
| Fried food (e.g. burgers, chips, samosas, fried chicken, pakoras) | <input type="text"/> | <input type="text"/> |
| High fat dairy food (e.g. cream, ghee, full fat milk, cheese, butter, ice cream) | <input type="text"/> | <input type="text"/> |
| Snacks (crisps, chocolates, cakes, sweets, bombay mix etc) | <input type="text"/> | <input type="text"/> |

Alcohol

Do you drink alcohol (includes drink brewed at
home)?

☐ Yes, more
than once
weekly

☐ Yes, less
than once
weekly

☐ No

If 'Yes, more than once weekly', estimate the number of
units of alcohol consumed each day last week...

| | | | |
|----------------------|-----------|----------------------|----------|
| <input type="text"/> | Monday | <input type="text"/> | Friday |
| <input type="text"/> | Tuesday | <input type="text"/> | Saturday |
| <input type="text"/> | Wednesday | <input type="text"/> | Sunday |
| <input type="text"/> | Thursday | | |

Smoking

Smoking status

☐ Smoker

☐ Non
smoker

☐ Ex
Smoker

Cigarettes per day

Motivation

What is the issue you want to address?

How important is this to you? Please score 1 - 10 (1 - Not at all, 10 - Extremely)

Why is this Important?

- | | |
|--|--|
| <input type="checkbox"/> Another's influence | |
| <input type="checkbox"/> Family/ friends beliefs about current behaviour | <input type="checkbox"/> Own beliefs about changing behaviour |
| <input type="checkbox"/> Health risks of continuing current behaviour | <input type="checkbox"/> Previous experience of addressing issue |
| <input type="checkbox"/> Likely response of other people | <input type="checkbox"/> Seriousness of issue |
| | <input type="checkbox"/> Other |

What would increase importance?

- ☐ Being willing to take necessary action
- ☐ Believing achieving goal is possible
- ☐ Desire to achieve goal
- ☐ Knowing that support is available
- ☐ Knowing what to do to achieve goal
- ☐ N/A (if importance is 10)
- ☐ Prioritising behaviour change
- ☐ Risk of getting worse
- ☐ Support of family / friends
- ☐ Other

How confident are you that this will be achieved? Please score 1 - 10
(1 - Not at all, 10 - Extremely)

What would increase confidence?

- ☐ Assurance of a confidential service
- ☐ Being satisfied with progress
- ☐ Clear, realistic goals
- ☐ Guaranteed support of family / friends
- ☐ Guaranteed support of health trainer
- ☐ Overcoming fear of failure
- ☐ Seeing others succeed

Notes

Wellbeing Measure (prior to intervention)

Section to be completed as required both before and after the programme.

Self - efficacy

1. I will be able to achieve most of the goals I set for myself

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

2. When facing difficult tasks, I am certain that I will succeed.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

3. In general, I think I can achieve outcomes that are important to me.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

4. I believe I can succeed at most tasks to which I set my mind.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

5. I will be able to successfully overcome many challenges.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

6. I am confident that I can manage well on many different tasks.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

7. Compared to other people, I can do most tasks very well.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

8. Even when things are tough, I can manage quite well.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

General Health

9. Please rate your current state of health by placing a cross on the line.

POOR

PER-
FECT

WHO–Five Well-being

1. I have felt cheerful and in good spirits.

☐ At no time ☐ Some of the time ☐ Less than half of the time ☐ More than half of the time ☐ Most of the time ☐ All of the time

2. I have felt calm and relaxed.

☐ At no time ☐ Some of the time ☐ Less than half of the time ☐ More than half of the time ☐ Most of the time ☐ All of the time

3. I have felt active and vigorous.

☐ At no time ☐ Some of the time ☐ Less than half of the time ☐ More than half of the time ☐ Most of the time ☐ All of the time

4. I woke up feeling fresh and rested.

☐ At no time ☐ Some of the time ☐ Less than half of the time ☐ More than half of the time ☐ Most of the time ☐ All of the time

5. My daily life has been filled with things that interest me.

☐ At no time ☐ Some of the time ☐ Less than half of the time ☐ More than half of the time ☐ Most of the time ☐ All of the time

INTERVENTION

GOAL SETTING – Individualised Health Plan

Date plan created

Primary issue being addressed

☐

Alcohol

☐

Exercise

☐

Diet

☐

Smoking

☐

Local issue

Relevant Issues

Primary goal

Primary goal date

Rewards

☐

Acknowledgement of friends / family

☐

Certificate for achieving goal

☐

Feedback at each session about what I have achieved

☐

Opportunity to encourage others to pursue same goal

☐

Other

☐

To be able to see results

Reminders

☐ Keeping a diary

☐ Post-event contact

☐ Regular contact

☐ Regular reminders and tips

☐ Support from significant other
(partner, friend)

☐ Other

Goals

| N o | Goal & Tar- get | Action(s) | Start Date | Target Date | Support | Achieved |
|--------|--------------------|-----------|------------|----------------|---------|---|
| 1 | | | | | | Achieved part achieved not achieved |
| 2 | | | | | | |
| 3 | | | | | | |
| 4 | | | | | | |
| 5 | | | | | | |
| 6 | | | | | | |

2nd -5th Meeting – Progress Review(s)

Review date

What was tried?

☐ Drinking less alcohol

☐ Reducing intake
of snacks

☐ Eating more fruit and vegetables

☐ Reducing portion
size

☐ Increasing amount of physical activity

| | | | | |
|--|--------------------------|-----------------------------------|--------------------------|------------------|
| | <input type="checkbox"/> | Reducing intake of fried food | <input type="checkbox"/> | Smoking less |
| | | | <input type="checkbox"/> | Stopping smoking |
| | <input type="checkbox"/> | Reducing intake of high fat foods | <input type="checkbox"/> | Other |

| | | | |
|----------------------|--------------------------|---------------|--|
| What was the result? | <input type="checkbox"/> | Achieved | |
| | <input type="checkbox"/> | Part Achieved | |
| | <input type="checkbox"/> | Not Achieved | |

| | | | | |
|-------------------------|--------------------------|---------------------------|--------------------------|------------------|
| What were the benefits? | <input type="checkbox"/> | Feel better | <input type="checkbox"/> | Made new friends |
| | <input type="checkbox"/> | Get on better with family | <input type="checkbox"/> | N/A |
| | | | <input type="checkbox"/> | Other |
| | <input type="checkbox"/> | Have more money | | |
| | <input type="checkbox"/> | Look better | | |

| | | | | |
|---|--|-------------------------------|--------------------------|--|
| What were the difficulties? (multiple tick list) | <input type="checkbox"/> | Clashes with other activities | <input type="checkbox"/> | Illness |
| | | | <input type="checkbox"/> | NA - No difficulties |
| | <input type="checkbox"/> | Clashes with other demands | <input type="checkbox"/> | Not enough support from friends/family |
| | | | <input type="checkbox"/> | Other |
| | <input type="checkbox"/> | Did not meet expectations | | |
| <input type="checkbox"/> | Doesn't seem to be making a difference | | | |

☐ Don't enjoy

How were they tackled?
(multiple tick list)

☐ Advice/encouragement
from a friend

☐ Advice/encouragement
from activity leader

☐ Advice from book/internet

☐ Advice/encouragement
from a friend

How were they tackled?
(multiple tick list)

☐ Advice/encouragement
from activity leader

☐ Advice from the GP/ Practice Nurse

☐ Advice from book/internet

| | | | | |
|---|--------------------------|--|--------------------------|--|
| What have you learned from working with the HT? (multiple tick list) | <input type="checkbox"/> | Am willing to take necessary action | <input type="checkbox"/> | Know how to set goals |
| | <input type="checkbox"/> | Being sure about what to do | <input type="checkbox"/> | Know what to do to achieve goal |
| | <input type="checkbox"/> | Believe achieving goal is desirable | <input type="checkbox"/> | Learned about the risks of the behaviour |
| | <input type="checkbox"/> | Believe achieving goal is possible | <input type="checkbox"/> | Need help to change behaviour |
| | <input type="checkbox"/> | Confidence in the service | <input type="checkbox"/> | Overcame anger with self |
| | <input type="checkbox"/> | Felt good about focusing on self | <input type="checkbox"/> | Overcame envy of those without my issues |
| | <input type="checkbox"/> | Have other issues to be addressed first | <input type="checkbox"/> | Overcame fear of failure |
| | <input type="checkbox"/> | How to prioritise goals over other objectives | <input type="checkbox"/> | Preferred learning style |
| | <input type="checkbox"/> | How to prioritise goals over meeting other needs | <input type="checkbox"/> | Realistic expectations of progress |
| | <hr/> | | | |
| What rewards were given / gained? (multiple tick list) | <input type="checkbox"/> | "me" time | <input type="checkbox"/> | Opportunity to encourage other(s) |
| | <input type="checkbox"/> | Certificate of achievement | <input type="checkbox"/> | Recognition for attendance |
| | <input type="checkbox"/> | Feedback on progress | <input type="checkbox"/> | Other |
| | <input type="checkbox"/> | Friends / family acknowledgement | | |

| | | | | |
|--------------------------------|--------------------------|-----|--------------------------|----|
| Are you confident to continue? | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No |
| Motivational Boost Conducted? | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No |

Physique (optional)

Height

Cm/ M/ Ft

Weight

Kg/St

☐

Yes

☐

No

Weight self reported

Waist Circumference

Cm / Inch

Exercise (optional)

Number of 30 minute sessions of moderate exercise per week

Number of 20 minute sessions of Vigorous exercise per week

Diet (optional)

Type of Food

How many days last week did you eat this kind of food?

On average, how many portions per day?

Fruit (e.g apples, bananas, mangoes, oranges)

Vegetables (e.g. carrots, broccoli, peas, okra, aubergine)

Fried food (e.g. burgers, chips, samosas, fried chicken, pakoras)

High fat dairy food (e.g. cream, ghee, full fat milk, cheese, butter, ice cream)

Snacks (crisps, chocolates, cakes, sweets, Bombay mix etc)

Alcohol (optional)

☐

Yes, more

☐

Yes, less

☐

Do you drink alcohol (includes drink brewed at home)?

than once
weekly

than once
weekly

N
o

| | | | | |
|---|----------------------|-----------|----------------------|----------|
| If 'Yes, more than once weekly', Estimate the number of units of alcohol consumed each day last week... | <input type="text"/> | Monday | <input type="text"/> | Friday |
| | <input type="text"/> | Tuesday | <input type="text"/> | Saturday |
| | <input type="text"/> | Wednesday | <input type="text"/> | Sunday |
| | <input type="text"/> | Thursday | | |

Smoking (optional)

| | | | | | | |
|--------------------|--------------------------|--------|--------------------------|--------|--------------------------|-----------|
| | <input type="checkbox"/> | | <input type="checkbox"/> | Non | | |
| Smoking status | <input type="checkbox"/> | Smoker | <input type="checkbox"/> | Smoker | <input type="checkbox"/> | Ex Smoker |
| Cigarettes per day | <input type="text"/> | | | | | |

5th Meeting Maintaining Change

Maintaining change
by

- | | |
|---|---|
| <input type="checkbox"/> Changing habits of current friends | <input type="checkbox"/> Other |
| <input type="checkbox"/> Changing habits of family | <input type="checkbox"/> Plan carefully before change |
| <input type="checkbox"/> Changing travel arrangements | <input type="checkbox"/> Prepare before going out |
| <input type="checkbox"/> Finding different interests | <input type="checkbox"/> Putting money aside for new activity |
| <input type="checkbox"/> Finding friends who share goal | |

Positive conse-
quences

- | | |
|--|---|
| <input type="checkbox"/> Feel better | <input type="checkbox"/> Learning something new |
| <input type="checkbox"/> Feel more confident | <input type="checkbox"/> Look better |
| <input type="checkbox"/> Have more money | <input type="checkbox"/> Make new friends |
| <input type="checkbox"/> Improve relationships | <input type="checkbox"/> Other |

Potential barriers

- | | |
|--|---|
| <input type="checkbox"/> Can't understand what is being said | <input type="checkbox"/> Have to miss a meeting & find it |
| <input type="checkbox"/> Childcare | <input type="checkbox"/> Difficult to restart |
| <input type="checkbox"/> Clashes with other activities | <input type="checkbox"/> Holidays |
| <input type="checkbox"/> Cost | <input type="checkbox"/> Illness |
| <input type="checkbox"/> Doesn't seem to be making a dif- ference | <input type="checkbox"/> Insufficient support from family/ friends |

☐ Don't enjoy ☐ Stress

☐ Family / friends still engage in behaviour

☐ Work

☐ Fear of failing

☐ Not applicable

How overcome problems?

☐ Advice from activity leader

☐ Get more info. from internet/ library

☐ Assert yourself

☐ Talk to a friend

☐ Contact health trainer for advice

☐ Other

Difficult situations

☐ Ask health psychologist to help restart

☐ Consider alternatives to chosen activity

Who might help?

☐ Activity leader

☐ Partner

☐ Friend

☐ Relative

☐ Health trainer

☐ Religious adviser

☐ Other

☐ Workmate

☐ Other people on programme

How might they help?

- ☐ Regular reminders of benefits
- ☐ Accompanying to activity
- ☐ Other
- ☐ Practical Advice
- ☐ Staying in contact
- ☐ Taking an interest in progress
- ☐ Trying out changes together

Review comments

Wellbeing Measure (AFTER INTERVENTION)

Self - efficacy

1. I will be able to achieve most of the goals I set for myself

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

2. When facing difficult tasks, I am certain that I will succeed.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

3. In general, I think I can achieve outcomes that are important to me.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

4. I believe I can succeed at most tasks to which I set my mind.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

5. I will be able to successfully overcome many challenges.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

6. I am confident that I can manage well on many different tasks.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

7. Compared to other people, I can do most tasks very well.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

8. Even when things are tough, I can manage quite well.

☐ Strongly disagree

☐ Disagree

☐ No preference

☐ Agree

☐ Strongly agree

General Health

9. Please rate your current state of health by placing a cross on the line.

POOR

PER-
FECT

WHO–Five Well-being

1. I have felt cheerful and in good spirits.

☐ At no
time

☐ Some of the
time

☐ Less than half of the
time

☐ More than half of the
time

☐ Most of the
time

☐ All of the
time

2. I have felt calm and relaxed.

☐ At no
time

☐ Some of the
time

☐ Less than half of the
time

☐ More than half of the
time

☐ Most of the
time

☐ All of the
time

3. I have felt active and vigorous.

☐ At no
time

☐ Some of the
time

☐ Less than half of the
time

☐ More than half of the
time

☐ Most of the
time

☐ All of the
time

4. I woke up feeling fresh and rested.

☐ At no
time

☐ Some of the
time

☐ Less than half of the
time

☐ More than half of the
time

☐ Most of the
time

☐ All of the
time

5. My daily life has been filled with things that in-
terest me.

☐ At no
time

☐ Some of the
time

☐ Less than half of the
time

☐ More than half of the
time

☐ Most of the
time

☐ All of the
time

Results

Completion date

Programme outcome

☐ ACHIEVED

☐ NOT ACHIEVED

☐ PART ACHIEVED

☐ OUTCOME UNKNOWN

Signpost To

Notes

Completion- Post Assessment Measures

Physique

| | | |
|---------------------|----------------------|-----------|
| Height | <input type="text"/> | Cm/ M/ Ft |
| Weight | <input type="text"/> | Kg/St |
| Waist Circumference | <input type="text"/> | Cm / Inch |

Exercise

| | |
|--|----------------------|
| Number of 30 minute sessions of moderate exercise per week | <input type="text"/> |
| Number of 20 minute sessions of Vigorous exercise per week | <input type="text"/> |

Diet

| Type of Food | How many days last week did you eat this kind of food? | On average, how many portions per day? |
|--|--|--|
| Fruit (e.g apples, bananas, mangoes, oranges) | <input type="text"/> | <input type="text"/> |
| Vegetables (e.g. carrots, broccoli, peas, okra, aubergine) | <input type="text"/> | <input type="text"/> |
| Fried food (e.g. burgers, chips, samosas, fried chicken, pakoras) | <input type="text"/> | <input type="text"/> |
| High fat dairy food (e.g. cream, ghee, full fat milk, cheese, butter, ice cream) | <input type="text"/> | <input type="text"/> |
| Snacks (crisps, chocolates, cakes, sweets, bom-bay mix etc) | <input type="text"/> | <input type="text"/> |

Alcohol

Do you drink alcohol (includes drink brewed at home)?

☐

Yes, more than once weekly

☐

Yes, less than once weekly

☐

No

If 'Yes, more than once weekly', Estimate the number of units of alcohol consumed each day last week...

| | | | |
|----------------------|-----------|----------------------|----------|
| <input type="text"/> | Monday | <input type="text"/> | Friday |
| <input type="text"/> | Tuesday | <input type="text"/> | Saturday |
| <input type="text"/> | Wednesday | <input type="text"/> | Sunday |
| <input type="text"/> | Thursday | | |

Smoking

Smoking status

☐

Smoker

☐

Non smoker

☐

Ex Smoker

Cigarettes per day

Proposed 6 months follow up assessment –Maintenance Check(s)

Maintenance date

Programme outcome

If a full Programme;

☐ Yes, Maintained

☐ No, not maintained

☐ Client not contactable

☐ Not applicable

If not a full Programme;

☐ Attended: Considered useful

☐ Attended: Not considered useful

☐ Not attended

Notes

Physique (optional)

Height

Cm/ M/ Ft

Weight

Kg/St

Waist Circumference

Cm / Inch

Exercise (optional)

Number of 30 minute sessions of moderate exercise per week

Number of 20 minute sessions of Vigorous exercise per week

Diet (optional)

Type of Food

How many days last week did you eat this kind of food?

On average, how many portions per day?

| | | |
|--|----------------------|----------------------|
| Fruit (e.g apples, bananas, mangoes, oranges) | <input type="text"/> | <input type="text"/> |
| Vegetables (e.g. carrots, broccoli, peas, okra, aubergine) | <input type="text"/> | <input type="text"/> |
| Fried food (e.g. burgers, chips, samosas, fried chicken, pakoras) | <input type="text"/> | <input type="text"/> |
| High fat dairy food (e.g. cream, ghee, full fat milk, cheese, butter, ice cream) | <input type="text"/> | <input type="text"/> |
| Snacks (crisps, chocolates, cakes, sweets, bom-bay mix etc) | <input type="text"/> | <input type="text"/> |

Alcohol (optional)

☐ Yes, more than once weekly
 ☐ Yes, less than once weekly
 ☐

Do you drink alcohol (includes drink brewed at home)?

| | | | | |
|---|----------------------|-----------|----------------------|----------|
| If 'Yes, more than once weekly', Estimate the number of units of alcohol consumed each day last week... | <input type="text"/> | Monday | <input type="text"/> | Friday |
| | <input type="text"/> | Tuesday | <input type="text"/> | Saturday |
| | <input type="text"/> | Wednesday | <input type="text"/> | Sunday |
| | <input type="text"/> | Thursday | | |

Smoking (optional)

☐ Smoker
 ☐ Non smoker
 ☐ Ex Smoker

Smoking status

Cigarettes per day

Appendix

Programme Goal & Target Options...

| Goal | Target | | | | ✓ |
|---------|-----------------------------------|-----------------------------------|--------------------------|--|--------------------------|
| Alcohol | Reduce | To 3 units or less (women) | <input type="checkbox"/> | To 4 units or less (men) | <input type="checkbox"/> |
| | | By half | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | By more than half | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | Quit | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | | | | |
| Diet | Change | Complete a food diary | <input type="checkbox"/> | Reduce evening food intake | <input type="checkbox"/> |
| | | Eat breakfast regularly | <input type="checkbox"/> | Reduce salt intake | <input type="checkbox"/> |
| | | Eat more regular meals | <input type="checkbox"/> | Reduce sugar intake | <input type="checkbox"/> |
| | | Increase starchy/wholegrain foods | <input type="checkbox"/> | Other | <input type="checkbox"/> |
| | | | | | |
| | Increase Fruit & Vegetable intake | by 1 portion per day | <input type="checkbox"/> | to five portions per day | <input type="checkbox"/> |
| | | by 2 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 3 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 4 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | | | | |
| | Increase Healthy Snacks | by 1 portion per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 2 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 3 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 4 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | | | | |
| | Increase intake of water | by 1 glasses per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 2 glasses per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 3 glasses per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | Reduce fatty food intake | by 1 meal per week | <input type="checkbox"/> | to 0 meals per week | <input type="checkbox"/> |
| | | by 2 meals per week | <input type="checkbox"/> | to less than 3 meals per week | <input type="checkbox"/> |
| | | by 3 meals per week | <input type="checkbox"/> | | <input type="checkbox"/> |
| | Reduce fizzy drink intake | by 1 glass per day | <input type="checkbox"/> | to 0 glasses / 0 cans per day | <input type="checkbox"/> |
| | | by 2 glasses / 1 can per day | <input type="checkbox"/> | to less than 2 glasses / 1 can per day | <input type="checkbox"/> |
| | | by 1 meal per week | <input type="checkbox"/> | | <input type="checkbox"/> |

| | | | | | |
|---------|-------------------------------|-----------------------|-----------------------------------|-----------------------------------|--------------------------|
| | Reduce fried food intake | by 2 meals per week | <input type="checkbox"/> | to 0 meals per week | <input type="checkbox"/> |
| | | by 3 meals per week | <input type="checkbox"/> | to less than 3 meals per week | <input type="checkbox"/> |
| | Reduce portion size | by one quarter (25%) | <input type="checkbox"/> | | <input type="checkbox"/> |
| | Reduce unhealthy snack intake | by 1 portion per day | <input type="checkbox"/> | to 0 portions per week | <input type="checkbox"/> |
| | | by 2 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 3 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | | by 4 portions per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | Reduce tea / coffee intake | by 1 cup per day | <input type="checkbox"/> | to less than 2 cups per day | <input type="checkbox"/> |
| | | by 2 cups per day | <input type="checkbox"/> | | <input type="checkbox"/> |
| | Exercise | Increase – Light * | by 1 (10 Minute) session per week | to 1 (10 Minute) session per week | <input type="checkbox"/> |
| | | | by 2 (10 Minute) session per week | to 2 (10 Minute) session per week | <input type="checkbox"/> |
| | | | by 3 (10 Minute) session per week | to 3 (10 Minute) session per week | <input type="checkbox"/> |
| | | | by 4 (10 Minute) session per week | to 4 (10 Minute) session per week | <input type="checkbox"/> |
| | | Increase – Moderate * | by 1 (30 Minute) session per week | to 1 (30 Minute) session per week | <input type="checkbox"/> |
| | | | by 2 (30 Minute) session per week | to 2 (30 Minute) session per week | <input type="checkbox"/> |
| | | | by 3 (30 Minute) session per week | to 3 (30 Minute) session per week | <input type="checkbox"/> |
| | | | by 4 (30 Minute) session per week | to 4 (30 Minute) session per week | <input type="checkbox"/> |
| | | | | to 5 (30 Minute) session per week | <input type="checkbox"/> |
| | | Increase – Vigorous * | by 1 (20 Minute) session per week | to 1 (20 Minute) session per week | <input type="checkbox"/> |
| | | | by 2 (20 Minute) session per week | to 2 (20 Minute) session per week | <input type="checkbox"/> |
| | | | by 3 (20 Minute) session per week | to 3 (20 Minute) session per week | <input type="checkbox"/> |
| | | | by 4 (20 Minute) session per week | to 4 (20 Minute) session per week | <input type="checkbox"/> |
| Smoking | Reduce | by half | <input type="checkbox"/> | to less than 10 per day | <input type="checkbox"/> |
| | | | <input type="checkbox"/> | to less than 5 per day | <input type="checkbox"/> |
| | Stop | Quit | <input type="checkbox"/> | | <input type="checkbox"/> |
| Other | | -- | <input type="checkbox"/> | | |

Appendix C

Reflections on the intervention delivery and implementation.

This was the first competency undertaken as part of the doctorate, and I was inexperienced in my role as a trainee. I believe that I was hindered by the practical challenges of implementing an intervention that not only fit the requirements of the competence, but also met the timescales and requirements of the directors and the clinical lead of the organisation. I believe that I was extremely ambitious in attempting to run the intervention within a forensic mental health setting. Although I had been proactive in arranging workplace supervision with an experienced and RMN there were no other Health Psychologists at the organisation that I could discuss issues with and I believe that the lack of awareness of Health Psychology within my work setting negatively impacted the initial stage of my training.

If I was to run the intervention again I would consider an alternative setting with more traditional health psychology input, where I would be able to receive work place supervision more familiar with the concepts involved. However, in the long-term I felt that these limitations helped strengthened my resolve and motivated me to be more exacting, methodological and thorough during the planning and implementation of future interventions. I believe that as my training progressed the experience of implementing the intervention raised my awareness of the challenges faced by a practitioner health psychologist and the key differences of delivering an intervention within this role. It also helped highlight the physical health issues faced by service users and illustrated the benefits of Health Psychology in optimising overall well-being for patients with mental health settings for the organisation. The experience

helped me to develop an altered perspective on the approach required to deliver an intervention and raised my awareness of the research implementation gap. Professionals who work in mental health frequently have to contend with extreme circumstances and symptoms, in often challenging situations and environments. This can occasionally lead to a rather insular approach and dismissive stance towards other health care professionals and their input. Delivering this intervention helped me recognise that although an intervention targeting healthy eating and balanced diet may not seem particularly extreme, it can have a tremendous impact on an individual's overall well-being and is thus, no less important.

SECTION D

SYSTEMATIC REVIEW

Psychological and social impact
of auto-immune alopecia

Abstract

Background

Alopecia is a common and distressing condition. It can have serious psychosocial consequences, causing severe emotional suffering as well as personal, social and work-related problems. There is a paucity of research exploring the psychosocial impact of the condition.

Objectives

The review looks to investigate the psychological and social impact of autoimmune alopecia and the factors associated with psychosocial well-being.

Method

Search strategy: Electronic searches were conducted using EBSCO and OVID platforms, for studies published from January 2007 until December 2017.

Reference lists of included studies were also searched.

Selection criteria: Studies which investigated the psychosocial impact of alopecia areata, alopecia totalis and alopecia universalis, using controlled observational studies, observational studies without a control group and qualitative study designs.

Data collection and analysis: The quality of the studies was assessed and data was synthesised using narrative synthesis.

Results

Fourteen studies were included in the review, with a total of 4415 participants from 10 different countries. The age range of participants was from 0 to 77 years and the duration of the disease varied from 1 week to 49 years. Twelve studies were quantitative and two were qualitative. The evidence suggested that alopecia is linked with psychological disorders and impacts upon the quality of life of those diagnosed. The negative impact of alopecia may be amplified for females, caused by societal pressure to be attractive.

Conclusion

Recognising the evident psychosocial impact of hair loss when treating patients with alopecia is critical. Research exploring the psychological treatments that may be effective in helping people adjust is required. Individual factors such as coping styles, age, gender and severity of the condition, which are associated with the course of psychosocial wellbeing in alopecia should also be considered.

Practitioners need to be aware of the psychosocial effects to enable holistic management of the disease.

Background

Alopecia is a general medical term for hair loss (Hon, Leung, & Ng, 2008). Hair loss may take various forms such as androgenetic alopecia, mediated by systemic androgens and genetic factors (Karaman, Dereboy, Dereboy, & Çarman, 2006), anagen effluvium, which is triggered by cancer treatment, telogen effluvium, caused by hormonal changes, severe stress, infections or certain medications (Shrivastava, 2009) and trichotillomania, initiated by a compulsive pulling out of one's own hair (Hon et al., 2008). In most cases hair loss is temporary. For instance, in anagen effluvium hair should start to grow back a few months after chemotherapy has ceased. In telogen effluvium hair will stop falling out and begin to regrow within six months (Han & Mirmirani, 2006).

The word alopecia is of Latin origin and literally translates as "hair loss". It is often used as a blanket term to cover all forms of hair loss including those that are a by-product of another illness. However, there are cases when the loss of hair is purely a condition in itself. This is referred to as autoimmune alopecia, which is a chronic dermatological condition, whereby hair follicles are attacked by the individuals own immune system and is manifested as patches of non-scarring hair loss (Alfani et al., 2012). There are three main subgroups of the illness, depending on the degree of hair loss; alopecia areata (AA) which refers to the partial loss of hair from the head in the form of patches, alopecia totalis (AT) referring to entire hair loss of all hair on the head and alopecia universalis (AU), which includes complete loss of all head, face and body hair (Wasserman, Guzman-Sanchez, Scott, & McMichael, 2007).

It has been suggested that 60% of cases of alopecia are individuals between the ages of 5 to 20 years old (Galán-Gutiérrez, Rodríguez-Bujaldón, & Moreno-Giménez, 2009). Nonetheless, it is argued that the condition can affect men and women at any point in their life, regardless of a person's ethnic or racial background (Bolduc & Shapiro, 2001). Its prevalence in the United Kingdom is estimated to be one to two people in every 1,000 (Hunt & McHale, 2005a).

The aetiology and subsequent development of alopecia are unclear. In the past, many researchers pointed to stress as a determining factor. However, it is now believed that while stress may be an aggravating factor, it is not the direct cause (Elkin, Hilker, & Drabman, 2006). Other factors that are linked to alopecia's development include abnormalities of the immune mechanism, anomalies in endocrine systems, genetic predisposition, infections and psychological disturbances (Ruiz-Doblado, Carrizosa, & García-Hernández, 2003).

A fundamental feature of autoimmune alopecia is the level of unpredictability regarding periods of remission and exacerbation. It is not yet possible to predict when hair will fall out, begin to grow, or to identify the relationship between alopecia and other medical conditions (Thompson & Shapiro, 1996). Given the seemingly random nature of alopecia, its management may be severely challenging (Bolduc & Shapiro, 2001). It is believed that out of the three types of autoimmune alopecia, AA sufferers are most likely to experience remission; yet may still go through repeated episodes of the illness throughout their lives (Meidan & Touitou, 2001). AT and AU are argued to be less responsive to medical treatment and in some cases not even possible to treat (Hunt & McHale, 2005b).

Additional factors linked with a less favourable prognosis are childhood onset, family history and when the hair loss is particularly severe (Van den Biggelaar, Smolders, & Jansen, 2010).

In terms of its physical impact, alopecia is non-life threatening and does not involve loss of mobility or physical pain. However, its unpredictability and visibility is thought to have a profound negative impact on one's psychological health (Williamson, Gonzalez, & Finlay, 2001). While being a medically benign condition, since hair is often considered to be a vital aspect of one's identity, alopecia can be perceived as a disfiguring disorder and therefore its psychological impact can be profound. It is frequently emotionally painful and damaging and may be destructive to one's personal and marital relationships, social wellbeing and career (Hunt & McHale, 2005b). In a review of 19 studies by Tucker (2009), alopecia areata was associated with impaired psychological well-being, occupational functioning, relationships and social interactions (Tucker, 2009). This could be explained by the fact that hair and facial hair convey messages about the individual's culture, gender, age, social class, economic status or religion (Batchelor, 2001). The importance placed on hair, body image, and beauty in our society is reflected in hair care products, magazines and other media. Hair is often perceived as a symbol of one's attractiveness, youth, good health or sexuality and its lack can be seen as a failure to fit into the norm of appearance within society (Kalabokes & Besta, 2001).

This review will update that of Tucker (2009), by drawing on the most recent literature (2007-2017), broadening the inclusion criteria to include all three types of

autoimmune alopecia and using systematic methodology. As well as investigate the factors associated with its psychosocial impact.

Aims

The aims of this systematic review were to examine the most recent literature on the psychological and social impact of autoimmune alopecia, and the demographic, clinical or psychological factors associated with this impact.

Method

Inclusion and exclusion criteria

Types of studies:

Both, quantitative and qualitative studies investigating the social and psychological impact of AA, AT and AU were included. Observational and qualitative studies were included. Commentaries, letters to editors, books, book chapters and studies of low quality methodological designs (refer to the Result section) were removed, as were those written in a language other than English,

Types of participants:

Participants with a diagnosis of autoimmune alopecia including AA, AT and AU, regardless of age, sex, race or ethnicity.

Types of outcomes:

Studies investigating the social or psychological impact of AA, AT, AU. Thus, studies exploring the consequences of the illness on one's psychological wellbeing

and the impact the illness has on one's ability to form satisfying relationships with others and to adapt to different social situations.

Search strategy for identification of studies:

Computerised searches were conducted using the EBSCO (CINAHL Plus with Full Text, E-Journals, Health and Psychosocial Instruments, MEDLINE Complete and PsychINFO) and OVID (Cochrane Central Register of Controlled Trials (CCTR) and EMBASE) platforms, in December 2017 for studies published from January 2007 to December 2017. The same strategy was used for all databases. An example of the search terms used is provided in Appendix A. The reference lists of included studies were also searched for relevant papers.

Study selection

All identified records were initially screened by their titles and abstracts by the author. Following the exclusion of records based on their titles and abstracts, a number of full text studies was investigated and those fulfilling the inclusion criteria were selected for the synthesis.

Data extraction

The data extraction form (Refer to figure 1) recorded the following features from the studies:

1. The condition.
2. Aims.
3. Study type and design.
4. Participant characteristics - age, gender, duration of the condition and severity of the condition.
5. Sample size and representativeness of the sample.
6. Sampling methods.
7. Outcome measures used - whether the researchers used validated and reliable measures to define outcomes.
8. Results and conclusions.

Table 1. Data Extraction

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|---|---|---|---|---|---------|
| 1 | <p>Aghaei, S., Saki, N., Daneshmand, E., & Kardeh, B. (2014), Iran.</p> <p>Aim: to assess the frequency of psychological disorders in patients with AA in comparison with normal subjects.</p> | <p>40 patients (18 males; 22 females).</p> <p>Mean age: NS.</p> <p>Duration of condition: NS.</p> <p>40 healthy controls (age-sex matched).</p> | <p>Quantitative</p> <p>Case-control study</p> | <p>Beck Depression Inventory (1961)</p> <p>Beck Anxiety Inventory (1988)</p> <p>Eysenck Personality Questionnaire (EPQ)</p> | <ul style="list-style-type: none"> <input type="checkbox"/> There was significant difference between patient and control group regarding depression ($p= 0.008$), anxiety ($p= 0.003$) and neurosis ($p= 0.05$). <input type="checkbox"/> There was no significant difference regarding extraversion ($p=0.249$), psychosis ($p=0.147$) and lying ($p=0.899$). <input type="checkbox"/> There was no significant correlation between duration of the disease, age of onset, number of relapses and intensity of the disease with anxiety, extraversion, neurosis, psychosis or lying ($p> 0.05$). <input type="checkbox"/> There were significantly higher rates of neuroticism ($p= 0.045$) and lying ($p= 0.005$) in AA involving the scalp. <input type="checkbox"/> There was significantly higher rate of depression ($p= 0.020$), anxiety ($p= 0.019$), and neurosis ($p= 0.029$) in AA involving face. <input type="checkbox"/> There was no significant higher rate of psychological illness ($p> 0.05$) in AA involving eyebrows. | 68% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|--|--|---|---|--|---------|
| 2 | <p>Alfani, S., Antonione, V., Moz-zetta, A., Di Pietro, C., Maz-zantp, C., Stella, P., Raskovich, D., & Abeni, D. (2012), Italy.</p> <p>Aim: to assess psychological status and the personality traits of patients with Alopecia Areata.</p> | <p>73 patients (33 males; 40 females).</p> <p>Mean age: 35.2 years (age range 18-73 years). Duration of condition: less than one year for 54.8%.</p> <p>73 healthy controls (age-sex matched).</p> | <p>Quantitative</p> <p>Case-control study</p> | <p>Minnesota Multiphasic Personality Inventory (MMPI-2)</p> | <ul style="list-style-type: none"> □ They were significant differences between the case and control groups regarding depression ($p=0.001$), hysteria ($p=0.006$), psychopathic deviance ($p=0.017$), psychasthenia ($p=0.006$), schizophrenia ($p=0.028$), anxiety ($p=0.001$), health concerns ($p=0.002$), bizarre thoughts ($p=0.028$) and family problems ($p=0.028$). □ The highest scores for the disease duration were observed for durations between 6 and 11 months. Statistically significant difference is seen respectively on paranoia and schizophrenia ($p<0.01$), hysteria, psychasthenia and anger ($p<0.05$), depression, antisocial practices and family problems ($p<0.10$) scales. □ The results suggest that males had significantly higher scores than females on psychopathic deviance, antisocial practices and family problems scales ($p<0.10$). | 55% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|---|--|---|---|--|---------|
| 3 | <p>Al-Mutairi, N. & Nour Eldin, O. (2011), Kuwait.</p> <p>Aim: to study the clinical profile of AA patients and impact of AA on the quality of life of patients with severe forms of the disease.</p> | <p>2962 patients (1926 males; 1036 females).</p> <p>Mean age: NS.</p> <p>Age range 0- >50; 58.03% of patients 21-40 years.</p> <p>Duration of condition: 2 weeks – several years.</p> | <p>Quantitative</p> <p>Case-control study</p> | Dermatology Life Quality Index Questionnaire (DLQI) | <ul style="list-style-type: none"> <input type="checkbox"/> The mean DLQI score in patients (age>21 years) with severe forms of AA was found to be 13.54 as compared to 1.24 in control group. <input type="checkbox"/> The DLQI scores increased with the severity of AA and were the highest in patients with AU. <input type="checkbox"/> There was no significant difference in the mean DLQI scores of males and females. <input type="checkbox"/> There was no significant correlation in the mean DLQI scores and the duration of illness. | 73% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|---|--|---|----------------------|--|---------|
| 4 | <p>Arbabi, N., Salami, F., Forouzes, F., Gharehbeeglou, M., Riyahin, A. A., & Shahrzad, M. E. (2013), Iran.</p> <p>Aim: to consider the effects of stressors in AA.</p> | <p>60 patients with AA (43 males; 17 females).</p> <p>Mean age: 29.45 (males) 30.48 (females).</p> <p>Duration of condition: NS.</p> <p>60 controls with unspecific hair loss.</p> | <p>Quantitative</p> <p>Case-control study</p> | Stress Questionnaire | <ul style="list-style-type: none"> <input type="checkbox"/> 52 AA patients had experienced a stressful event 3 months before appearance of the disease as compared to 18 controls, $p=0.001$. <input type="checkbox"/> The majority of AA patients (30) had two stressful events while most patients of the control group (9) mostly experienced one stressful event, $p=0.001$. <input type="checkbox"/> The frequency of patients with severe stress in AA was significantly higher (70%) compared to control group (31.7%), $p< 0.05$. <input type="checkbox"/> With regards to stress perception, 93.1% of patients with AA and 15% of controls believed in the effects of stress on the process of their disease ($p= 0.005$). | 64% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|--|--|---|---|---|---------|
| 5 | <p>Ataseven, A., Saral, Y., & Godekmerdan, A. (2011), Turkey.</p> <p>Aim: to investigate the association between AA and depression, anxiety and cytokines.</p> | <p>43 patients with AA (31 males; 12 females).</p> <p>Mean age: 23.42.</p> <p>Duration of condition: 15.54 months (ranged from 1 month to 19 years).</p> <p>30 age and sex matched healthy controls.</p> | <p>Quantitative</p> <p>Case-control study</p> | <p>Hamilton Rating Scale for Depression (HAM-D)</p> <p>Hamilton Rating Scale for Anxiety (HAM-A)</p> <p>Children's Depression Inventories (CDIs) for children between 7 and 16 years old.</p> | <p><input type="checkbox"/> Some degree of depression was observed in 50% of the AA patients as compared to 30% of the controls ($p<0.05$).</p> <p><input type="checkbox"/> Anxiety was found in 63% of AA patients over 16 years old as compared to 23% of the controls ($p<0.05$).</p> <p><input type="checkbox"/> No significant differences were observed between patients and controls with respect to serum cytokine levels ($p<0.05$).</p> | 73% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|--|---|---|--|--|---------|
| 6 | <p>Baghestani, S., Zare, S., Seddigh, S. H. (2015), Iran.</p> <p>Aim: to investigate severity of depression and anxiety in patients with AA.</p> | <p>68 patients with AA (49 males; 19 females).</p> <p>Mean age: 35.4.</p> <p>Duration of condition: 22.7 months.</p> <p>68 age, sex and education level matched healthy controls.</p> | <p>Quantitative</p> <p>Case-control study</p> | <p>Hamilton Anxiety Rating Scale (Ham-A)</p> <p>Hamilton Depression Rating Scale (Ham-D)</p> | <ul style="list-style-type: none"> <input type="checkbox"/> 47% AA patients suffered from anxiety <input type="checkbox"/> The mean of anxiety scale in case group was significantly higher than that of control group (12.76 vs 8.54; P=0.003). <input type="checkbox"/> 56% AA patients suffered from depression. <input type="checkbox"/> The mean of depression scale in case group was significantly higher than that of control group (12.84 vs 6.22; P=0.001). <input type="checkbox"/> Patients with AA were exposed to depression approximately 5 times more than normal people. <input type="checkbox"/> Patients with AA were exposed to anxiety about 3 times more than normal people. | 64% |
| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |

| | | | | | | |
|---|--|--|---|---|---|-----|
| 7 | <p>Cartwright, T., Endean, N., & Porter, A. (2009), U.K.</p> <p>Aim: to investigate the relationships between illness perceptions, coping and Quality of Life in patients with Alopecia.</p> | <p>214 patients (43 males; 171 females).</p> <p>Mean age: 35 years.</p> <p>Duration of condition: 13.7 years (the mean).</p> | <p>Quantitative</p> <p>A cross-sectional design</p> | <p>The Revised Illness Perception Questionnaire</p> <p>The Dermatology Life Quality Index</p> <p>The brief COPE</p> | <ul style="list-style-type: none"> <input type="checkbox"/> Alopecia perceived to have major consequences on participants' lives (IPQ-R 3.56). <input type="checkbox"/> Alopecia perceived to have considerable emotional impact (IPQ-R 3.76). <input type="checkbox"/> The QOL in the sample was impaired (DLQI 12.49, $p<0.05$). <input type="checkbox"/> QOL was significantly poorer for women with Alopecia (DLQI 13.01; $p<0.05$) compared to men (DLQI 10.42, $p<0.05$) <input type="checkbox"/> Women significantly more likely to feel Alopecia interfering with leisure activities (DLQI 3.32, $P<0.01$) than men (DLQI 2.23, $p<0.01$). <input type="checkbox"/> Women significantly more likely to feel Alopecia interfering with personal relationships (DLQI 2.01, $p<0.01$) than men (DLQI 1.28, $p<0.01$) <input type="checkbox"/> Men significantly more likely to feel that Alopecia affected their work (DLQI 1.56, $p<0.05$) than women (DLQI 1.22, $p<0.05$). <input type="checkbox"/> DLQI was positively correlated with: psychological attributions (DLQI 0.150, $p<0.05$), belief in the serious consequences of Alopecia (DLQI 0.589, $p<0.01$), emotional interpretations of the condition (DLQI 0.545, $p<0.01$) and illness identity (DLQI 0.377, $p<0.01$). <input type="checkbox"/> QOL was negatively correlated with illness coherence (DLQI -0.161, $p<0.05$). | 55% |
|---|--|--|---|---|---|-----|

| | | | | | | |
|--|--|--|--|--|---|--|
| | | | | | <input type="checkbox"/> Impaired QOL was associated with problem focused coping (DLQI 0.374, $p<0.01$) and avoidant coping (DLQI 0.519, $p<0.01$). <input type="checkbox"/> Age at onset, number of hair losses and duration of the condition were not associated with Quality of Life. | |
|--|--|--|--|--|---|--|

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|---|--|--|---|---|---------|
| 8 | <p>Ghajarzadeh, M., Ghiasi, M., & Kheirkhah, S. (2011), Iran.</p> <p>Aim: to determine QOL impairment and depression in Iranian patients with AA.</p> | <p>100 patients (69 males; 31 females).</p> <p>Mean age: 23 years.</p> <p>The mean duration of condition: 12.8 months.</p> | <p>Quantitative</p> <p>Cross-sectional study</p> | <p>Beck Depression Inventory (BDI)</p> <p>Short Form Health Survey SF-36</p> <p>Dermatology Life Quality Index questionnaire (DLQI)</p> | <ul style="list-style-type: none"> <input type="checkbox"/> There was no significant association between DLQI and the duration of the disease ($p=0.6$). <input type="checkbox"/> There was no significant association between DLQI and age ($p=0.1$). <input type="checkbox"/> There was significant association between DLQI and BDI score ($p<0.001$). <input type="checkbox"/> 61% of participants experienced some form of depression. <input type="checkbox"/> BDI scores were significantly different for male (12.7) and female (18.1) participants ($p=0.01$). <input type="checkbox"/> SF-36 and DLQI did not significantly differ between two groups (DLQI 6.4 vs. 6.2, $p=0.8$; SF-36 68.1 vs. 67.7, $p=0.8$). | 64% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|---|---|--|--------------------------------------|--|---------|
| 9 | <p>Masmoudi, J., Sellami, R., Ouali, U., Mnif, L., Feki, I., Amouri, M., Turki, H., & Jaoua, A. (2013), Tunisia.</p> <p>Aim: to examine the impact of AA on the different dimensions of QOL and to determine factors related to an altered QOL.</p> | <p>50 patients (24 males; 26 females).</p> <p>Mean age: 32.92 years (range 18 - 60 years)</p> <p>Duration of the condition: NS</p> <p>80% had patchy Alopecia with less than 50% involvement, 12% had patchy Alopecia with 50–99% involvement, and 8% had AT.</p> <p>50 age and sex matched healthy controls.</p> | <p>Quantitative</p> <p>Case-control study.</p> | The Short Form Health Survey (SF36). | <ul style="list-style-type: none"> □ Compared with the general population, AA patients presented a significantly altered quality of life, found in the global score (SF-36 68.95, $p<0.001$) and in five sub-scores of the SF-36: mental health (SF-36 63.64, $p<0.001$), role emotional (SF-36 33.33, $p<0.001$), social functioning (SF-36 54.60, $p<0.001$), vitality (SF-36 62.40, $p<0.001$) and general health (SF-36 68.95, $p<0.001$). □ Females scored lower on the SF-36 than males in global score ($p=0.007$), physical functioning ($p=0.028$), general health ($p=0.012$) and role emotional ($p=0.018$). □ The younger the patient, the more their mental health is negatively affected by AA ($p=0.017$). □ Unmarried patients had significantly lower scores in the dimension of mental health compared to married patients ($p=0.050$). □ There is a relationship between poorer QOL and severity of AA. The relationship was significant in the SF-36 subscale of mental health ($p=0.07$) and social functioning ($p=0.009$). | 73% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|--|---|--|--|---|---------|
| 10 | <p>Qi, S., Xu, F., Sheng, Y., & Yang, Q. (2015), China.</p> <p>Aim: to assess QOL of AA patients in China and determine the relationship of DLQI scores to demographic and clinical variables.</p> | <p>698 patients with AA (349 males; 349 females)</p> <p>Mean age: 38.8 years.</p> <p>Duration of condition: 16.9 years.</p> | <p>Quantitative</p> <p>Cross-sectional</p> | <p>Dermatology Life Quality Index Questionnaire (DLQI)</p> | <ul style="list-style-type: none"> <input type="checkbox"/> QOL of 40.9% patients was moderately to extremely affected by AA. <input type="checkbox"/> QOL was impaired significantly in severe AA patients ($p < 0.001$). <input type="checkbox"/> Duration longer than 12 months, disease recurrence and presence of scalp symptoms were associated a higher DLQI score ($p < 0.001$). <input type="checkbox"/> Younger patients exhibited higher DLQI score ($p < 0.05$). <input type="checkbox"/> There was no effect on QOL by sex. | 59% |
| 11 | <p>Rafique, R., Hunt, N. (2015), Pakistan.</p> <p>Aim: to investigate experiences and coping behaviours of adolescents with AA.</p> | <p>8 AA patients (3 males; 5 females)</p> <p>Mean age: 17.5 years.</p> <p>Duration of condition: 1-3 years.</p> | <p>Qualitative.</p> | <p>Semi-structured interviews</p> <p>IPA</p> | <p>Four main keys were identified:</p> <ol style="list-style-type: none"> 1. Loss (self/social). 2. Concerns (physical/future). 3. Negative (emotions/thoughts). 4. Coping styles (adaptive/maladaptive). <ul style="list-style-type: none"> <input type="checkbox"/> Females experienced greater feeling of loss, were more concerned about their looks/future and reported more negative thoughts/emotions. <input type="checkbox"/> Females felt angry and blamed God; males blamed their fate and luck. <input type="checkbox"/> Action-oriented and practical coping styles adopted by all. | 80% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|--|--|---|--|---|---------|
| 12 | <p>Rocha de Holanda, T., Sodré, C.T., Brasil, M. A., & RamoseSilva, M. (2014), Brazil.</p> <p>Aim: to assess QOL in AA patients in Brazil.</p> | <p>37 AA patients (14 males; 23 females).</p> <p>Mean age: 35.89 years.</p> <p>Duration of condition: not stated.</p> <p>49 and sex matched blood donors controls.</p> | <p>Quantitative</p> <p>Case-control study</p> | <p>The Short Form Health Survey (SF36)</p> | <ul style="list-style-type: none"> <input type="checkbox"/> The impairment in QOL in AA patients on social functioning ($p=0.001$), emotional role functioning ($p=0.019$), and mental health ($p=0.000$) scales displayed statistically significant difference in relation to the control group. <input type="checkbox"/> In the AA group the mental health subscale's score was not influenced by sex ($p=0.139$), age ($p=0.603$) and severity of Alopecia ($p=0.130$). <input type="checkbox"/> AA seems to greatly affect patients worldwide. | 68% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|--|--|--|---|--|---------|
| 13 | <p>Sellami, R., Masmoudi, J., Ouali, U., Mnif, L., Amouri, M., Turki, H, & Jaoua, A. (2013), Tunisia.</p> <p>Aim: to investigate a possible relationship between AA and Alexithymia, Anxiety and Depression.</p> | <p>50 patients (24 males; 26 females).</p> <p>Mean age: 32.92 years (range 18-60 years).</p> <p>Duration of the condition: 69.28 days (range 1-400 days).</p> <p>50 healthy controls</p> | <p>Quantitative</p> <p>Case control study</p> <p>Cross sectional</p> | <p>Hospital Anxiety and Depression Scale (HADS).</p> <p>The Toronto Alexithymia Scale (TAS)</p> | <ul style="list-style-type: none"> <input type="checkbox"/> There was no significant difference between AA patients and controls in terms of alexithymia prevalence ($p=0.683$). <input type="checkbox"/> Anxiety ($p=0.005$) and depression ($p=0.047$) were significantly higher in the patient group in comparison with controls. <input type="checkbox"/> Unmarried patients showed significantly more signs of depression compared to healthy controls ($p=0.024$). <input type="checkbox"/> Female patients are differentiated from males by higher levels of anxiety and depression ($p=0.016$). | 82% |

| ID | Author, date, location & aim | Sample characteristics | Study Type and Study Design | Psychosocial outcome | Findings | Quality |
|----|---|---|-----------------------------|---|--|---------|
| 14 | <p>Welsh, N. & Guy, A. (2009), U.K.</p> <p>Aim: to capture respondent's ongoing lived experience of AA.</p> | <p>12 patients (5 males; 7 females).</p> <p>Mean age: 45 (men), 37 (women); (range from 31 to 59 years).</p> <p>The mean duration of condition: 14.6 years (men), 20.7 (women); (range from 2 -49 years).</p> | Qualitative | <p>Semi-structure interviews</p> <p>IPA</p> | <p>IPA generated 2 superordinate themes and 6 subthemes:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Coping with the initial impact of Alopecia <ul style="list-style-type: none"> • social dimensions, treatments • social support <input type="checkbox"/> Living with unpredictability of Alopecia. <ul style="list-style-type: none"> • time to adjust • pragmatic coping • putting things into perspective • positive thinking <p>An IPA also found that:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Adjustment is related to a range of psychosocial factors and coping techniques change and improve with time. <input type="checkbox"/> AA is considered to have a disruptive impact on self-image and self-esteem. <input type="checkbox"/> Women reported higher concern regarding their appearance than men. <input type="checkbox"/> Women reported using support groups whereas men did not. | 70% |

Quality assessment

This review included a number of study designs and different sample sizes so in order to effectively evaluate the quality of the studies reviewed, several quality tools were considered. This included QUADAS (Whiting, Rutjes, Reitsma, Bossuyt, & Kleijnen, 2003), COSMIN (Mokkink et al. 2010), AMSTAR (Shea, et al., 2007) and QualSyst (Kmet, Lee, & Cook, 2004). Upon reviewing various checklists, it was decided that QualSyst was most appropriate for the current review. QualSyst is a standardised review tool for assessing the quality of qualitative and quantitative studies. Its scoring system draws upon existing published tools for quantitative and qualitative research and the systematic review tool implements both systems (Kmet, Lee, & Cook, 2004) (Appendix C & D). The checklist for quantitative studies consists of 14 items that are scored 'yes'=2, 'partial'=1, 'no'=0, determined by the degree to which particular criteria are fulfilled. Items 'not applicable' to a specific study design are excluded from the calculation. A summary score was calculated for each study by adding the total score obtained from the relevant items and dividing by the total possible score (28). The checklist for qualitative studies consists of 10 items that are also scored 'yes'=2, 'partial'=1, 'no'=0. There was no 'n/a' option and the summary score was calculated for each study by adding the total score obtained from each item and dividing by the total possible score (20). Quality was evaluated independently by two assessors. Where disagreement occurred within an item, these were discussed and the checklists were reviewed until consensus was reached.

Data synthesis

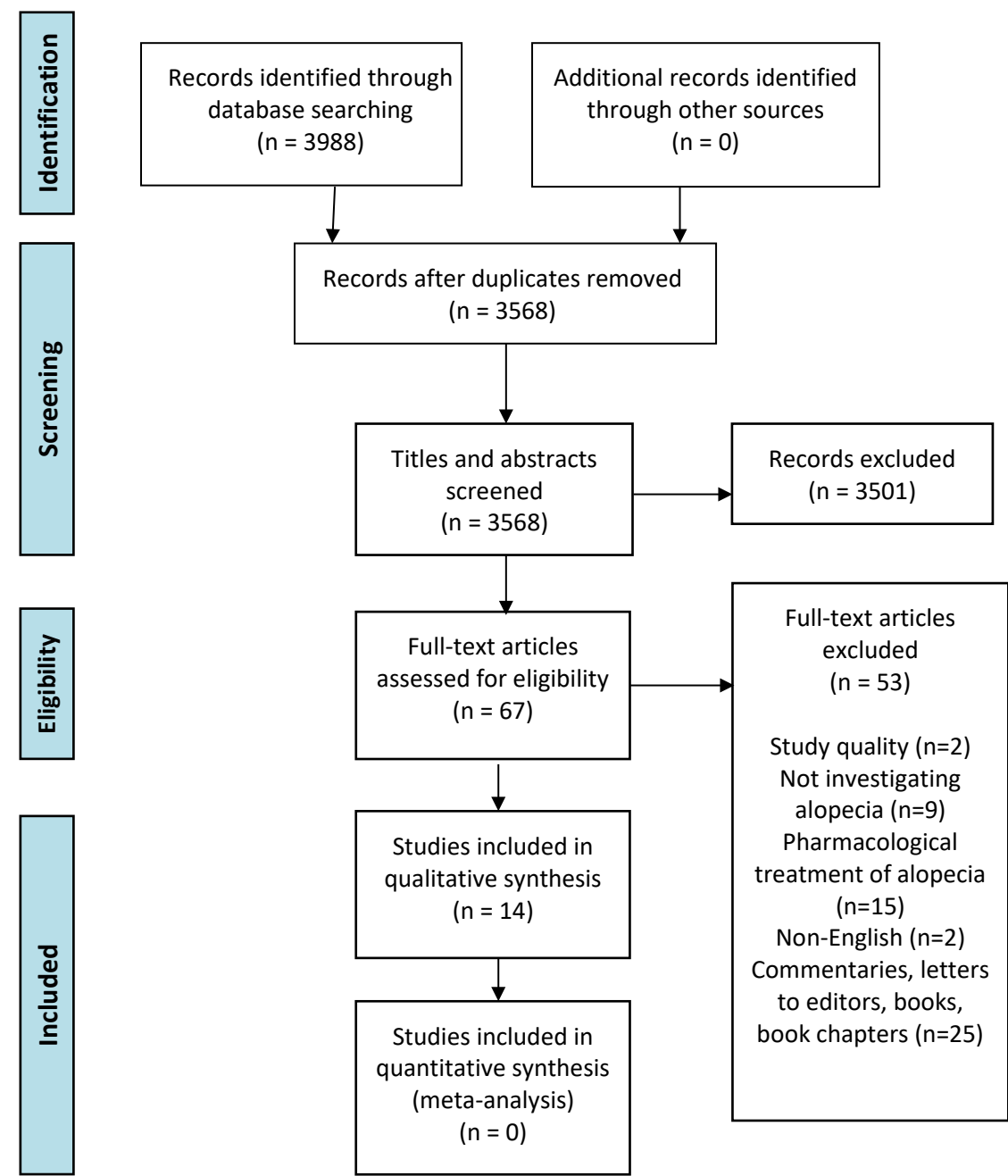
The study follows PRISMA guidelines on how to conduct and report systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009). In-line with guidance from Popay et al., (2006), a narrative synthesis was used to summarise the data and to reflect critically on the synthesis process.

Results

Study selection

The search initially identified 3,568 studies, after duplicates had been removed (Refer to figure 2). These 3568 records were screened and 3501 records excluded based on their titles and abstracts. After checking the full texts, 53 records were excluded and in total 14 studies met the inclusion criteria of this review.

Figure 1: PRISMA Flowchart



Quality assessment

Quantitative and qualitative studies were assessed for quality separately. For quantitative studies, inter-rater agreement in scoring by item ranged from 57% to 100% (Appendix E). The overall scores assigned by the Reviewer 1 ranged from 0.55 to 0.86 and by the Reviewer 2 from 0.55 to 0.82 (Appendix G). The reviewers assigned the same overall score to three studies. For the remaining eleven studies, discrepancies in the overall scores ranged from 0.04 to 0.05. For the qualitative studies, inter-rater agreement in scoring by item ranged from 50% to 100% (Appendix G). The overall scores assigned by Reviewer 1 ranged from 0.70 to 0.85 and by Reviewer 2 from 0.75 to 0.80 (Appendix H). The discrepancy in the overall score was 0.05.

The overall quality of the quantitative studies varied from 55% to 86%. The weakest studies had design flaws, for example, they lacked conclusions, insufficiently described their objectives and had no control group. The overall quality of the two qualitative studies varied from 70% to 85%. The weaker studies included insufficient descriptions of their theoretical framework and lacked conclusions.

Study characteristics

The 14 included studies represented 4415 participants from 10 different countries (Belgium, Brazil, China, Italy, Iran, Kuwait, Pakistan, Tunisia, Turkey and the United Kingdom). Twelve studies were quantitative (8 case-control design; 4 cross-sectional design) and 2 were qualitative. The size of the samples varied from 8 to 2962 participants. Of the 8 case control studies, 5 of those had an equal number of patients and age-sex matched controls (Aghaei et al., 2014; Alfani et al., 2012;

Arbabi et al., 2013; Baghestani et al., 2015; Sellami et al., 2013).

Participant characteristics

Participants included 2631 males and 1784 females from 10 different countries.

The age range of participants was from 0 to 77 years and the duration of the disease varied from 1 week to 49 years. The youngest age of onset was less than 1. The studies included participants with AA, AT, AU. The severity of the illness varied from small patches on the scalp and loss of facial hair to the complete loss of all facial and body hair.

Psychosocial impact of alopecia

Depression

Six of the 14 studies measured depression, using a validated scale. Five studies were case-control studies, one was a cross-sectional study. The control groups consisted of healthy age-sex matched controls. The studies' quality score ranged from 0.55 to 0.82. Of these 6 studies, all found that the rates of depression (Aghaei, Saki, Daneshmand, & Kardeh, 2014; Alfani et al., 2012; Ataseven, Saral, & Godekmerdan, 2011; Baghestani, Zar & Seddigh, 2015; Ghajarzadeh, Ghiasi, & Kheirkhan, 2011; Sellami, et al. 2013) were statistically, significantly higher for those with alopecia compared to controls not diagnosed with the condition. Additionally, Ghajarzadeh, Ghiasi and Kheirkhah (2011) found a statistically significant negative association between quality of life and depression scores.

Anxiety

Five of the 14 studies measured anxiety, using a validated scale. All 5 were case-control studies and again the control groups consisted of healthy age-sex matched controls. The studies' quality score ranged from 0.55 to 0.82. Of these 5 studies, all found that the rates of anxiety (Aghaei, Saki, Daneshmand, & Kardeh, 2014; Alfani et al., 2012; Ataseven, Saral, & Godekmerdan, 2011; Baghestani, Zar & Seddigh, 2015; Sellami, et al. 2013;) were statistically significantly higher, for those with alopecia compared to healthy controls.

Psychiatric morbidity

One of the 14 studies measured psychiatric comorbidity, using a validated scale. This case-control study, with healthy age-sex matched controls had a quality score of 0.55. This study found that rates of schizophrenia and psychopathic deviance (Alfani et al., 2012) were significantly higher for those with alopecia than controls, but no significant differences were found between cases and controls on levels of paranoia or hypomania (Alfani et al., 2012).

Quality of life

The 6 studies included in this systematic review that measured this outcome suggest a strong association between alopecia and quality of life, using validated scales.

Disease-specific quality of life

Four studies used the validated Dermatology Life Quality Index Questionnaire (DLQI) (Finlay & Khan, 1994). Al-Mutairi and Eldin (2011) argued that mean scores were statistically poorer in patients with alopecia than in the healthy age and sex matched control group. Using established criteria for the scale, Cartwright, Endean and Porter (2009) found low mean scores on DLQI scale, which indicated that the quality of life of patients with alopecia was significantly impaired. Qi, Xu, Sheng and Yang (2015) also suggested that quality of life was affected moderately to extremely impaired in 41% of alopecia patients.

Generic quality of life

Two studies measured generic quality of life. When compared with the general population, people with alopecia presented with significantly poorer quality of life on the global score of the 36-Item Short Form Health Survey (SF-36) (Masmoudi et al. 2013) and in its mental health (Masmoudi et al. 2013; Rocha de Hollanda, Sodr , Brasil, & Ramos-e-Silva, 2014), social functioning (Masmoudi et al. 2013; Rocha de Hollanda, Sodr , Brasil, & Ramos-e-Silva, 2014), role emotional, vitality and general health subscales (Masmoudi et al., 2013).

Stress

Arbabi et al. (2013) found that 87% of alopecia patients had experienced a stressful event 3 months before the appearance of the disease, as compared to 30% of controls, who experienced un-specific hair loss. Similarly, Alfani et al (2012)

found that 24.6% of the sample reported stressful events at the onset or before the exacerbation of alopecia, 10 reported family problems, five reported work problems and three reported mourning.

Factors associated with psychosocial well-being

Gender

According to the majority of the reviewed studies gender is a factor associated with psychosocial adjustment. Masmoudi et al. (2013) found that females scored lower than males on global quality of life, physical functioning, general health and emotional role functioning using a generic quality of life measure. Using a dermatology specific measure, Cartwright et al. (2009) found that quality of life was poorer for women with alopecia compared to men and women were more likely to feel that alopecia interfered with personal relationships. On the contrary, Ghajarzadeh et al. (2011) and Qi et al. (2015) found no effect on quality of life for gender.

Significantly higher rates of depression (Ghajarzadeh et al., 2011; Sellami et al., 2013; Baghestani et al., 2015) and anxiety (Sellami et al., 2013; Baghestani et al., 2015) were found for female participants as compared to males. Alfani et al. (2012) also suggested that males scored significantly higher than females on psychopathic deviance.

In the two qualitative studies, Welsh and Guy (2009) found that alopecia had a disruptive impact on self-image and self-esteem; females reported higher concern regarding their appearance than males and consequently reported using support groups, whereas males did not. Similarly, Rafique and Hunt (2015) claimed that there were differences in the way men and women perceive loss. Consequently, as a result of the condition females reported loss of self-esteem and loss of confidence, whereas men reported loss of confidence and loss of love from friends. In addition, men were more likely than women to express concerns about looking older and women were more likely to report concerns about looking less attractive (Rafique & Hunt, 2015). Only female patients reported negative emotions, for example, feelings of guilt and depression (Rafique & Hunt, 2015). The researchers also suggested that coping techniques may differ between men and women, for instance with regards to intro-punitive avoidance, women reported withdrawing from social life and men starting smoking. As for self-distraction males reported playing more sports and women reported spending more time studying. Support seeking was mostly evident in women's reports and using humour was typical to males (Rafique & Hunt, 2015).

Age

Both Qi et al. (2015) and Masmoudi et al. (2013) found that being younger was associated with poorer quality of life. In Qi et al. (2015) this was found for those under 40 years of age and was regardless of disease severity. Whereas, Ghajarzadeh et al. (2011) did not find a significant association between quality of life and age and Baghestani et al. (2015) failed to find a significant association between age and severity of anxiety or depression in alopecia.

Education level

Baghestani et al. (2015) found a statistically significant relationship between those with primary and secondary education level and prevalence of depression and anxiety, levels of anxiety and depression were higher in patients with secondary education compared to patients with primary education levels.

Marital status

Although Masmoudi et al. (2013) concluded that unmarried patients had significantly lower scores in mental health quality of life compared to married patients, the p value of 0.05 suggests that this is non-significant. Whilst Sellami et al. (2013) found that unmarried patients with higher depression scores had a significantly greater risk for having AA compared to those with lower depression scores. In their qualitative study, Rafique and Hunt (2015) reported that female patients feared not being able to experience love and not getting married.

Family history

Qi et al. (2015) failed to find any relationship between quality of life and family history of alopecia.

Age of onset

No significant relationships were found between quality of life (Qi et al., 2015), anxiety, neurosis or psychosis (Aghaei et al., 2014) and age of onset.

Disease type, severity and location

Several studies looked at the impact of alopecia disease type on psychosocial well-being, the results were somewhat inconsistent. Whilst Al-Mutairi and Eldin (2011) found that patients with complete facial and body hair loss, that is AU, had poorer quality of life compared to patients with AA and AT. Qi et al. (2015) found that presence of scalp symptoms (AA), were associated with poorer quality of life when compared with AT and AU. Ghajarzadeh et al. (2011) however, found that the poorest quality of life was found for patients whose eyebrows were moderately involved compared to eyelash or beard involvement.

Masmoudi et al. (2013) found that those with 51-75% hair loss had significantly poorer mental health and social functioning quality of life than those with less than 25% hair loss. Patients with 100% hair loss also scored poorer on mental health quality of life compared to those with 51-75% hair loss. Significantly higher rates of depression, anxiety and neurosis were also found in AT, which involves losing facial hair (Aghaei et al., 2014), but no association with eyebrow involvement. Whereas, Baghestani et al. (2015) did not find significant differences in anxiety and depression scores based on severity or the onset location of the disease. Similarly, Sellami et al. (2014) found no relationship between the severity of alopecia and depression.

Disease duration

Qi et al. (2015) found that disease recurrence and an illness duration of longer than 12 months, compared to a shorter duration, was associated with poorer quality of

life. However, Ghajarzadeh et al. (2011) did not find significant relationship between quality of life and the duration of the illness. Whilst Alfani et al. (2012) reported the highest rates of psychopathic deviance, paranoia, schizophrenia and depression if the duration of the disease was between 6-11 months, compared to less than 6 months or more than 11 months. There was however, no association between disease duration and rates of anxiety, hypomania or social discomfort. According to Baghestani et al. (2015) there was no significant association between anxiety and depression scores and disease duration.

Coping strategies

Two qualitative studies explored coping strategies and how people use these to manage the psychosocial consequences of living with alopecia. In a group of adolescents with alopecia areata Rafique and Hunt (2015) identified 4 themes linked to psychosocial impact on alopecia patients: loss, concerns, negative emotions (discussed in the gender section) and coping styles. The researchers argued that patients can be characterised by maladaptive coping, such as blaming or intropunitive coping, as well as adaptive coping behaviours, for example action-oriented, practical, religious, self-distraction, support seeking, acceptance, future planning and humorous coping. The data indicated that coping mechanisms change and improve over time and initial maladaptive coping behaviours are replaced by more adaptive ones as disease duration increases. Similarly, in a qualitative study of 12 people with AA or AU, Welsh and Guy (2009) found that adjustment is related to a range of coping techniques, which change and improve with time. Pragmatic coping, putting things into perspective and positive thinking

are the most common coping strategies to deal with the psychological burden of the condition.

Discussion

The aims of the systematic review were to evaluate the psychological and social impact of autoimmune alopecia, and the factors associated with this impact. In agreement with a previous review (Tucker, 2009), all 14 papers included observed adverse psychosocial consequences to having alopecia and extending the findings of Tucker (2009) this impact was associated with a number of demographic, clinical and psychological factors.

Supporting the findings of Tucker (2009), a majority of the studies included in the current review reported poorer quality of life and higher rates of depression and anxiety amongst patients with alopecia compared to those not affected by the condition. There was less robust evidence to suggest a link between alopecia and diagnosed psychiatric morbidities, but a potential role for stressful life events as a trigger for alopecia. This finding could be explained by the fact that levels of depression and anxiety in patients with alopecia maybe high enough to make stress perception more pronounced (Arbabi et al., 2013).

A number of factors were found to play a potential role in people's reports of psychosocial wellbeing, including disease severity and location, disease duration, gender, age and marital status. Overall, quality of life declined with the severity of alopecia, with hair loss involving the scalp and eyebrows being particularly problematic for quality of life and loss of facial hair for anxiety and depression. The significance of facial and scalp hair loss suggests that it may be the visibility of the disorder that is having the greatest impact on wellbeing. In support of this, Kacar et

al. (2016) argued that the inability to conceal an illness may lead to self-stigmatisation and consequently individuals with alopecia report more stigma compared to patients with mental health disorders. Strategies to hide alopecia differ according to the extent of hair loss and the stage of the illness. Welsh and Guy (2009) argued that people often tried to conceal the initial patches by wearing scarves, hats, headbands, using sprays, covering patches with the remaining hair or make up. At later stages people alter the type of clothing they wear and try to cover their heads (Masmoudi et al., 2013). Women often use veils and wigs, men tend to use hair pieces, caps or they shave their hair (Rafique & Hun, 2015). The ability to hide one's alopecia, reportedly helped people to regain their confidence and reinstate their social and professional roles (Welsh & Guy, 2009).

Overall, the impact of disease duration on wellbeing was mixed. Qualitative research suggested that the coping mechanisms people utilise to manage the consequences of their alopecia may improve over time and initially maladaptive coping behaviours are replaced with more adaptive ones (Rafique and Hunt, 2015). Early disease seemed to also be related to poorer quality life and higher levels of depression and psychiatric morbidity, although these findings were not consistent. This implies that the patient's experiences amplified depression and anxiety in the first episode of the illness and over time, they start to accept the condition as a part of their lives and adopt more effective coping strategies. It could however, also indicate that pre-existing psychological disorders may initiate or aggravate the disease or that alopecia can result from a stressful life event.

Being female was also associated with poorer quality of life and higher rates of anxiety and depression in the majority of the included studies. Qualitative research by Welsh and Guy (2009) also argued that alopecia had a more disruptive impact on female self-image and self-esteem and on male self-confidence. These findings suggest that psychological interventions may need to be adapted to target different areas for men compared to women. Hair has traditionally been viewed as essential to the identity of many women as femininity, sexuality and attractiveness are symbolically linked to a woman's hair (Wolf, 1991). In a study of cancer patients with Alopecia, hair loss was ranked amongst the most worrisome side effects and it was often described as distressing, and having a negative impact on the body image (Lemieux, Maunsell, & Provencher, 2008).

For some women, the loss of hair is reported as being psychologically more difficult than the loss of a breast through breast cancer (Freedman, 1994). Alopecia can clearly have serious psychosocial consequences, causing intense emotional suffering, as well as personal, social and work-related difficulties. Surveys have shown that around 40% of women with alopecia have had marital problems, and around 63% claimed to have career-related problems (Hunt & McHale, 2005a). Supporting the marital and relational effects of alopecia found within this review. Results suggest that an un-established social life in unmarried patients may lead them to worry about their future, resulting in increased anxiety. Hair loss could be viewed as an abnormality and as a failure to conform to society's norms of ideal physical appearance, which has the potential to set people apart in their own estimation and in the estimation of others. Rafique and Hunt (2015) also noted differences in coping strategies, suggesting a tendency for women to withdraw from

social life and for men to take up smoking. This qualitative work also noted that in order to distract themselves from thinking about the illness, men used humour and tended to take part in more sports and women spent a greater amount of their time studying. Females are also most likely than males to seek support from others (Welsh and Guy, 2009; Rafique & Hunt, 2015). According to these researchers, coping mechanisms change and improve over time and initial maladaptive coping behaviours may be replaced by more adaptive ones.

Being younger was associated with poorer quality of life, particularly for those under 40 years of age, but was not associated with mood. This suggests that younger patients, of working age, may feel more pressure due to scenarios such as applying for a job or seeking a partner than older patients. Data on psychosocial consequences of alopecia in children and adolescents was found to be very limited, adolescents were only researched in one study (Rafique & Hunt, 2015). This concept should be studied more adequately as although age of onset was not found to impact on psychosocial wellbeing in this review approximately 60% of patients with alopecia develop the illness before the age of 20 (Kakourou, Karachristou, & Chrousos, 2007). The condition may severely impact identity formation in children and adolescents (Hunt & McHale, 2005a) and impair psychosocial and physical areas of children's and adolescents' quality of life (Bilgiç, et al. 2014). Consequently, further research exploring the link between alopecia and its psychosocial impact in children and adolescents is recommended.

Strengths and limitations of the review

Strengths of the current review include a systematic and thorough literature search, the high number of good quality studies, incorporating the most recent research, the use of studies from a variety of countries, the use of validated scales and double quality assessment checks. Limitations of the review include lack of double study selection, the majority of studies not utilising large samples, most participants being recruited from hair clinics and therefore samples being prone to selection bias, providing less evidence for causal inference than longitudinal or experimental designs, although the later would have been less appropriate for this research question.

Conclusions

Recognising the psychosocial impact of hair loss is critical when caring for patients with alopecia. It seems clear that alopecia can have a profound psychological impact on those affected by the condition and hence further research exploring the psychological treatments that may be effective in helping people adjust is required. Individual factors, such as coping styles, age, gender and severity of the condition, that are associated with the course of psychosocial wellbeing in alopecia should also be considered. Practitioners should recognise that alopecia is a medical rather than cosmetic condition and should be aware of the various psychosocial effects to enable holistic management of the disease.

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APPENDIX A. Search Strategy

| | |
|----|---|
| S1 | (MH "Alopecia+") |
| S2 | (MH "Alopecia+") 20070101-20171231 |
| S3 | Alopecia areata OR Alopecia Totalis OR Alopecia Universalis |
| S4 | S2 OR S3 |
| S5 | S4 NOT (Chemotherapy OR Cancer OR Effluvium OR Androgen* OR Cicatrical OR Trichotillomania) |
| S6 | "psycho*" |
| S7 | "emotion*" OR "adjust*" OR "adapt*" OR "cop*" OR "self*" OR "depress*" OR "anx*" OR "stress*" OR (MM "Quality of Life") |
| S8 | S5 AND S6 AND S7 |

Appendix B. Quality Assessment Tool for quantitative studies (Kmet, Lee, & Cook, 2004).

| Criteria | | Yes (2) | Partial (1) | No (0) | N/A |
|----------|---|------------|----------------|-----------|-----|
| 1 | Question/objective sufficiently described? | | | | |
| 2 | Study design evident and appropriate? | | | | |
| 3 | Method of subject/comparison group selection or source of information/input variables described and appropriate? | | | | |
| 4 | Subject (and comparison group, if applicable) characteristics sufficiently described? | | | | |
| 5 | If interventional and random allocation was possible, was it reported? | | | | |
| 6 | If interventional and blinding of investigators was possible, was it reported? | | | | |
| 7 | If interventional and blinding of subjects was possible, was it reported? | | | | |
| 8 | Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported? | | | | |
| 9 | Sample size appropriate? | | | | |
| 10 | Analytic methods described/justified and appropriate? | | | | |
| 11 | Some estimate of variant is reported for the main results? | | | | |
| 12 | Controlled for confounding? | | | | |
| 13 | Results reported in sufficient detail? | | | | |
| 14 | Conclusions supported by the results? | | | | |

Appendix C. Quality Assessment Tool for qualitative studies (Kmet, Lee, & Cook, 2004).

| Criteria | | Yes (2) | Partial (1) | No (0) | N/A |
|----------|--|------------|----------------|-----------|-----|
| 1 | Question/objective sufficiently described? | | | | |
| 2 | Study design evident and appropriate? | | | | |
| 3 | Context for the study clear? | | | | |
| 4 | Connection to a theoretical framework/wider body of knowledge? | | | | |
| 5 | Sampling strategy described, relevant and justified? | | | | |
| 6 | Data collection methods clearly described and systematic? | | | | |
| 7 | Data analysis clearly described and systematic? | | | | |
| 8 | Use of verification procedure(s) to establish credibility? | | | | |
| 9 | Conclusions supported by the results? | | | | |
| 10 | Reflexivity of the account? | | | | |

Appendix D. Inter-rater agreement by item for quantitative studies.

| Checklist Item | Observed Agreement for Each Checklist Item (%) |
|-----------------------|---|
| 1 | 79% |
| 2 | 86% |
| 3 | 71% |
| 4 | 57% |
| 5 | 100% |
| 6 | 100% |
| 7 | 100% |
| 8 | 100% |
| 9 | 93% |
| 10 | 86% |
| 11 | 100% |
| 12 | 79% |
| 13 | 64% |
| 14 | 71% |

Appendix E. Inter-rater agreement by item for qualitative studies.

| Checklist Item | Observed Agreement for Each Checklist Item (%) |
|----------------|--|
| 1 | 100% |
| 2 | 50% |
| 3 | 100% |
| 4 | 100% |
| 5 | 100% |
| 6 | 100% |
| 7 | 50% |
| 8 | 100% |
| 9 | 100% |
| 10 | 100% |

Appendix F. Inter-rater agreement for overall scores of quantitative studies.

| Research Paper | Rater 1 | Rater 2 | Agreed score |
|-------------------------------------|----------------|----------------|---------------------|
| 1. Aghaei et al. (2014) | 0.72 (72%) | 0.68 (68%) | 0.68 |
| 2. Alfani et al. (2012) | 0.55 (55%) | 0.59 (59%) | 0.55 |
| 3. Al-Mutairi & Nour Eldin (2011) | 0.77 (78%) | 0.73 (73%) | 0.73 |
| 4. Arbabi et al., (2013) | 0.64 (64%) | 0.64 (64%) | 0.64 |
| 5. Ataseven et al. (2011) | 0.73 (73%) | 0.73 (73%) | 0.73 |
| 6. Baghestani et al. (2015) | 0.68 (68%) | 0.64 (64%) | 0.64 |
| 7. Cartwright et al. (2009) | 0.59 (59%) | 0.55 (55%) | 0.55 |
| 8. Ghajarzadeh et al. (2011) | 0.68 (68%) | 0.64 (64%) | 0.64 |
| 9. Masmoudi et al. (2013) | 0.77 (77%) | 0.73 (73%) | 0.73 |
| 10. Qi et al. (2015) | 0.64 (64%) | 0.59 (59%) | 0.59 |
| 12. Rocha de Hollanda et al. (2014) | 0.68 (68%) | 0.68 (64%) | 0.68 |
| 13. Sellami et al. (2013) | 0.86 (86%) | 0.82 (82%) | 0.82 |

Appendix G. Inter-rater agreement for overall scores of qualitative studies.

| Research Paper | Rater 1 | Rater 2 | Agreed Score |
|---------------------------|----------------|----------------|---------------------|
| 11. Rafique & Hunt (2015) | 0.85 (85%) | 0.80 (80%) | 0.80 |
| 14. Welsh & Guy (2009) | 0.70 (70%) | 0.75 (75%) | 0.70 |